

University of Stirling

School of Health Sciences

**Exploring decision making and patient
involvement in prosthetic prescription**

Karen Alison Semple

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List of abbreviations

ARC	Army Recovery Capability
DASA	Defence Analytical Services Advice
DMRC	Defence Medical Rehabilitation Centre, Headley Court
DMS	Defence Medical Service
DPTS	Defence Patient Tracking System
DSC	Disablement services centre
EWA	Early walking aid
IED	Improvised explosive device
KCMHR	King's Centre for Military Health Research
PCT	Primary Care Trust
PRAC	Primary Rehabilitation and Assessment Centre
PRC	Primary Rehabilitation Centre
PRU	Personnel Recovery Unit
RCDM	Royal Centre for Defence Medicine, Queen Elizabeth Hospital Birmingham
RRU	Regional Rehabilitation Unit
SOTA	State of the art
UHBFT	University Hospital Birmingham Foundation Trust

Glossary of terms

Transfemoral amputation - Above knee amputation

Transhumeral amputation - Above elbow amputation

Transradial amputation - Below elbow amputation

Transtibial amputation - Below knee amputation

Distal - Situated further away from the centre of the body. The hand is distal to the shoulder.

Proximal - Situated nearer to the centre of the body or the point of attachment. The elbow is proximal to the wrist.

Prosthetic socket - The interface between the patients stump and the rest of the components of the prosthetic limb, encapsulates a portion of the residual limb to transmit the forces exerted by the prosthetic limb to the patients' skeletal structure.

Femurett - An early walking aid, used in physiotherapy for a trans-femoral amputee

Doffing - Taking off the prosthesis

Donning - Putting on the prosthesis

PPAM aid - An early walking aid, used in physio to reduce swelling and increase mobility

Abstract

Background

Recent conflicts have seen an increase in trauma related military amputees who incur complex injuries which result in varied residual limbs. In many cases these amputees have been provided with state of the art (SOTA) components with the expectation that they will transfer into NHS care after military discharge. However, there is a lack of knowledge around how prosthetic prescriptions are made in both the MOD and NHS, including patient involvement. It is important to explore prosthetic prescription decisions to enhance the quality, consistency and equity of care delivery for trauma amputees. This thesis explores decision making in prosthetic care for trauma amputees in the UK during this period of change.

Aims

To explore aspects of prosthetic care provision in the UK including clinical decision making, patient experience and the transition of prosthetic care from the MOD to the NHS.

Design

An exploratory qualitative project informed by decision making and patient involvement theory. Semi-structured interviews were carried out with nineteen clinical staff involved in prosthetic provision, six civilian and five veteran trauma amputees. Thematic analysis was used to analyse the data.

Findings

Prosthetists used a wide range of factors in making prescription decisions, including physical characteristics, patients' goals, and predicted activity levels. Prescription decision making varied depending on the prosthetists' level of experience and the different 'cues' identified. In some cases there was a lack of transparency about drivers for the prescription choice.

Prescription decisions are influenced by long term relationships between prosthetist and patient, allowing a trial and error approach with increasing patient involvement over time. Patient experiences of their trauma amputation influenced their approach to rehabilitation. Patients reported wanting different levels of involvement in their prosthetic care, however, communication was essential for all. Veteran amputees benefited from peer support opportunities which NHS services were less conducive to. However, NHS amputees were more likely to have been 'involved' in care decisions. The expectations that MOD patients had of inferior care in the NHS were not realised in the majority of veteran cases.

Recommendations

Research is needed to support prosthetists' decisions to become more consistent and transparent. The NHS should consider introducing a peer support model for trauma patients, and particularly in the early stages of rehabilitation.

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Personal Statement

My interest in this topic comes from my background as a prosthetist. Prosthetists are allied health professionals who provide artificial limbs or prostheses to patients who have lost or were born without a limb. Prosthetists design the prosthesis, oversee its assembly and fit the completed prosthesis to the patient, making the necessary adjustments to maximise its performance during fitting. The aim is to restore or provide function for the patient caused by the absence of a limb.

I graduated from the University of Strathclyde with a BSc Hons in Prosthetics and Orthotics in 2008. After graduating I worked as a research assistant at the National Centre for Prosthetics and Orthotics (NCPO) on a number of orthotics based research projects. My professional interests were more closely aligned with the field of prosthetics rather than orthotics and it was this field which I wanted to pursue. During my time there in 2009 I had the opportunity to meet with prosthetists working in the NHS across Scotland who raised concerns about the understanding that there would be an increase in military amputees being discharged from the Armed Forces and joining their NHS services. This was an issue which was raised several times during my time at the NCPO. I wanted to continue within research, however most of the research undertaken at NCPO focussed on the technical aspects of prosthetics while I was interested in patient/ professional centred research. I realised I would have to look further afield to gain the research experience required in order to pursue my own research interests. To this end I applied for a job at the Nursing, Midwifery and Allied Health Professions Research Unit based at the University of Stirling (NMAHP Research Unit).

The NMAHP Research Unit is a Scottish Government funded research unit with a remit to conduct applied research within the areas of nursing, midwifery and allied healthcare professionals (AHP) practice. As a trained AHP I felt that this was a good fit and I spent the next 18 months gaining further research experience through two maternity focussed projects. Towards the end of my contract I started to develop a proposal for this PhD research and was able to start the PhD in May 2011 with funding provided by the NMAHP Research Unit and the State of the Art (SOTA) prosthetics group. Throughout this thesis I refer to patient participants as amputees, while I recognise that this is not the most holistic term for this group it is a commonly used term in prosthetic rehabilitation research. Other ways of referring to this group were considered, however, it was felt that they could prove cumbersome in a document of this length.

1 Chapter 1 - Introduction

Between 2001 and 2014 British Military Forces were playing an active role in conflicts in the Middle East, primarily Afghanistan. North Atlantic Treaty Organisation (NATO) troops, including British Military Forces, had been deployed in Afghanistan as part of the 'War on Terror' since 2001. In 2006 military efforts were increased resulting in greater numbers of fatalities and amputee casualties. In 2012 Prime Minister David Cameron announced that the number of British troops in Afghanistan would be reduced from the end of 2012 in preparation for ending their military operations there. On the 26th of October 2014 British troops handed over the last UK base to the control of Afghan security forces. As well as the conflict in Afghanistan, Britain was also involved in military operations in Iraq from 2003 to 2011, however, between 2009 and 2011 there were only a very small number of British troops deployed there. Over this period of sustained conflict in these two countries UK troops suffered considerable numbers of casualties. These military injuries included a rise in personnel suffering limb loss and amputation resulting from critical injuries. The number of UK military personnel whose injuries have included a traumatic or surgical amputation from these two conflicts between 2001 and mid 2015 is currently 313 (Ministry of Defence 2015a). A proportion of these personnel will require prosthetic care for the remainder of their lives. While the Ministry of Defence (MOD) definition of amputation is broad¹, their most recent report indicates that 106 of these cases are 'significant multiple amputees'. In addition to the amputees resulting from operations in Iraq and Afghanistan there were a further 71 reported amputees among military personnel within the same time periods (Ministry of Defence 2015a). Injured military personnel are now more likely to be discharged, this is reflected in the number of Iraq and Afghanistan amputees reported to have been medically discharged since their amputation. Of the 384 amputees reported by the MOD in this time period 61%, two hundred and thirty four, have since been medically discharged from the Armed Forces and for those receiving prosthetic care the on-going responsibility for their prosthetic care now lies with the NHS.

It has been documented that the injuries that amputees were experiencing in these conflicts were more complex than patients from previous conflicts had sustained due to the nature of weapons being used, in particular the use of improvised explosive devices (IEDs). In addition anecdotal accounts were circulating that these military patients were being provided with state of the art (SOTA) components which were not available through NHS based prosthetic services in Scotland. In 2009 the potential impact of a 'surge' of this group

¹ The MOD definition for amputation is as follows 'Includes partial or complete amputations for wither upper or lower limbs and can range from loss of part of a finger or toe up to the loss of entire limbs' ((Ministry of Defence 2015a)

of patients on the NHS was therefore raised a cause of concern. This concern was raised in relation to possible impact on NHS prosthetic budgets and a lack of the required expertise within the NHS to treat patients with complex injuries who were being provided with prosthetic components not routinely prescribed by the NHS. These fears came from within NHS prosthetic services, prosthetic education providers and charitable bodies involved in health care for veterans and in particular, amputees.

At that time no arrangements had been made for the management of the anticipated increase (described as a surge) in the number of amputee veterans. Concerns continued to escalate from this time and in 2010/2011 a report was commissioned to evaluate the prosthetic care available to amputee veterans within the NHS (Murrison 2011). This report was commissioned at the height of the conflict in Afghanistan with seventy five reported amputations resulting from injuries during the period 2010/2011. The report was published in October 2011 and all twelve of its recommendations were accepted by Government without dispute. It was within this context of uncertainty about the impact of an anticipated surge in numbers of amputee veterans that this research was conducted.

1.1 Prosthetic provision

The provision of appropriate prostheses is essential to the wellbeing of patients as they have the potential to enhance or inhibit the patients' sense of self, their ability to achieve what they hope to, their physical function and personal goals. Prosthetists are the key professionals with the responsibility to provide prostheses. As such they must consider many aspects of care; the prosthetic components and materials which are available and what is suitable for the patient, the patient's past and desired future level of activity, knowledge of what can realistically be achieved after rehabilitation, cost and availability of products.

Despite its importance, little research evidence is available to inform prosthetic decision making. Only in the last 20 years has there been an emergence of studies using qualitative research designs exploring patients' experiences of amputation and prosthetic use in order to influence prosthetic rehabilitation delivery (Murray and Forshaw 2013). While the development of new components and prosthetic design are prolific there is a recognised lack of high quality research on the efficacy of individual components (Van der Linde et al 2004a). For these reasons it is acknowledged within the profession that clinical experience and craft knowledge plays a major role in the prescription of devices. This was highlighted by Hafner (2005) when he concluded that scientific literature in prosthetics seems more to *support* clinical experience rather than to affect clinical conclusions. A series of studies were undertaken in the Netherlands with the aim of developing prescription guidelines for

lower limb prosthetics (Van der Linde et al 2003; Van der Linde et al 2004a; Van der Linde et al 2004b; Van der Linde et al 2005). The conclusions of their 2004 study showed that in situations where there was little evidence based literature available the prescribers' clinical experience based knowledge was of importance in the prescription process (Van der Linde et al 2004b). Furthermore, despite the life changing impact of amputation and the importance of having a prosthesis that is appropriate for the patients' needs, there is little research on the way in which patients' values and preferences are taken into account in making prosthetic treatment decisions or on the ways in which patients are involved in the decision making process.

1.2 Rationale and Aims

The on-going prosthetic care and provision for these veteran amputees could conceivably extend to 60 years or more depending on the age of the patient at the time of amputation. Recognition of the long term nature of prosthetic care is important combined with the fact that in the majority of veteran cases their long term care is the responsibility of the NHS. The difficulty for the NHS is the lack of information provided by the MOD about their criteria for providing SOTA components, which they must then maintain and provide in the longer term. Indeed, little is known about prosthetic prescribing practices in either the MOD or the NHS. Therefore, in the context that some amputees were being prescribed SOTA products with unclear rationale (or consideration of sustainability) while others were receiving more standard products. At the same time there has been increasing national interest in veteran care coupled with emerging criticism from charities of the NHS prosthetic service and its ability to cope with the anticipated surge of veteran amputees, discharged with SOTA components by the MOD. In this context it was timely that more research was undertaken to understand the prosthetic prescribing process in both of these settings.

My original aim was to compare decision making and experiences of prosthetists and trauma amputees in the NHS and MOD settings. However, after a long process of consultation and applications permission was not granted for access to interview these groups within the MOD setting. For these reasons the aims of the project were reframed to focus solely on the NHS setting for prosthetic prescription decision making while maintaining the focus on experience of care in both the MOD and NHS. The overarching aims of the reframed project were:

1. to explore prosthetists' decision making in prosthetic prescription in the NHS.
2. to explore patients' experiences of prosthetic care and their involvement in their care
3. to explore the transition of prosthetic care from amputees moving from the military setting to the NHS after discharge from the Armed Forces.

These aims were addressed by the following research questions:

1. What are the issues and drivers for prosthetic service delivery for trauma amputees, in particular, current and anticipated service related amputees?
2. What factors (clinical and non-clinical) are used in the judgements and decision making of prosthetists during prosthetic prescription for civilian trauma amputees and service attributable amputees?
3. What are trauma patients' experiences of prosthetic care in the UK?
4. What are the experiences of involvement in decision making in the NHS and the MOD of traumatic civilian and service attributable amputees?
5. What are the experiences of transition of prosthetic care for those amputees moving from the MOD to the NHS?

This thesis is comprised of eight chapters. This, Chapter one, provides an introduction for the following seven chapters. Chapter two describes the background of amputation and prosthetic rehabilitation in the UK. Chapter three describes a scoping study which was conducted in three parts: part one comprises a review of relevant literature; part two comprised a policy document review and part three interviews with key stakeholders from the MOD and NHS. Chapter four describes the project methods. Chapter five gives an overview of decision making and patient involvement literature. Chapters six and seven contain the findings of the two empirical studies which were conducted. Finally, Chapter eight contains a discussion of the key findings in relation to existing literature and recommendations for further research, policy and practice.

2 Chapter 2 - Background

The standard of prosthetic care in the UK has been identified as being subject to a great deal of variability between the forty-four disablement services centres (DSCs) providing these services in the NHS. This variability has been attributed in part to the structure of prosthetic care delivery in the NHS. More recently this service has become subject to further contextual and organisational factors which have just begun to be explored (Murrison 2011). In order to begin to understand the impact that the additional population of military amputees will have on prosthetic service in the UK it is important to understand the way that the NHS service currently works and within which constraints.

2.1 Amputation and prosthetics

Historically, amputation was one of the earliest documented surgical procedures having been carried out for therapeutic, ritualistic and punitive reasons for thousands of years (Magee 1998). Indeed, amputation is still practiced in a number of Middle Eastern countries including Yemen, Sudan, Iran and Afghanistan as a form of punishment (Mavroforou et al 2014). Evidence of ritualistic amputation of fingers and toes among a number of African tribes was reported in the 1960's (Kirkup 2007b) as well as the practice of 'yubitsume'; self-amputation of fingers among Japanese mafia which still occurs today (Bosmia et al 2014). Amputation involves the removal of one or more of the bodies' extremities, either through surgery, constriction or trauma. Worldwide, trauma can be seen as the major cause of amputation. However, in the developed world the number of amputations resulting from trauma have reduced dramatically over the last century due to a decline of worker numbers in industries such as mining and farming. In addition, this period saw the introduction of stringent workplace Health and Safety policies in many countries. Consequently, in Western society, amputation is now most commonly seen as a result of complications of vascular disease in the ageing population.

Around 5000 amputees are referred annually to prosthetic services in the UK (The Amputee Statistical Database for the United Kingdom 2009). This includes patients who have congenital limb deficiency or have had amputations associated with dysvascularity, trauma, infection, neoplasm and more. While the most common causes of amputation in the UK are complications of vascular disease, the involvement of UK forces in conflicts in the Middle East has led to a rise in military related traumatic amputations. These military cases are different mainly because of the mode of injury, commonly by improvised explosive devices (IEDs).

There are incidents of triple amputations among this group, which rarely occurs in the civilian population, whose prosthetic needs can be very complex. On discharge from the Armed Forces, responsibility for veteran healthcare passes to the NHS with the implicit requirement that they continue to provide the level of prosthetic equipment (often described as 'state of the art') provided by the MOD. As the number of amputees being discharged from the Armed Forces continues to rise, and is forecast to do so until 2020, an unprecedented stress is placed on NHS prosthetic resources (Dharm-datta et al 2011; Murrison 2011). Murrison (2011) estimated that the veteran amputee caseload in the NHS was 333 in 2011 rising to 1032 in 2031. This position is likely to severely test NHS prosthetic budgets. While the numbers of discharged military amputees are relatively small compared to the overall amputee population in the UK, their multiple amputations and complex requirements will still have a considerable impact on NHS prosthetic services.

2.1.1 Rate and causes of amputation in the UK

Amputation is a life changing and traumatic experience for anyone, involving major surgery which alters both personal function and self-image. There are two broad groups of patients who require amputation. Most common are those requiring amputation as a result of complications arising from long standing diseases affecting the circulatory system, such as peripheral vascular disease (PVD) or complications from diabetes. These diseases most commonly affect older age groups in the population. In the UK trauma accounted for only seven percent of lower limb amputations in 2006/7 with PVD being recorded as causing 72% in the same year. Patients over the age of 65 accounted for over half of all prosthetic referrals, with the average age of those undergoing amputation in Britain being 66 years (The Amputee Statistical Database for the United Kingdom 2009). The age profile of the trauma amputees is vastly different. Figures from 2006/7 showed that 74% of this group were in the 16-54 year age bracket. Further, amputations resulting from long term conditions are generally planned allowing time for considered decisions to be made about optimum surgery and prosthetic management. In these situations the patient also has some time prior to the amputation to prepare psychologically, to consider the post amputation options and how the amputation will affect their lives (Butler et al 1992).

In cases of trauma amputation the situation is completely reversed. Although the route to amputation can vary the initial injury is characteristically shocking and sudden. Limbs may be lost at the site of injury which means that the patient has no time to prepare psychologically and surgeons are unable to pre-plan the optimum level for amputation. If the limb has not been lost at the point of initial injury, but has been significantly damaged then the decision must be taken to either amputate or to attempt to salvage the limb. Surgical procedures relating to limb salvage have advanced hugely over the last thirty years. However, it can require many

surgical procedures over a long period of time to achieve long term function and there remains the debate about the superiority of limb salvage over amputation (Penn-Barwell et al 2015). If unsuccessful, the decision may be taken subsequently between the surgeon and the patient to perform an elective amputation. A study exploring the factors influencing the decision to have an elective amputation after injury identified three key factors; pain, function and participation (Quon et al 2011). It also identified that for most participants this was a decision process which occurred over several years.

In modern conflicts, blast injuries are the most common threat to serving personnel. Under the broad category of IEDs a number of weapons are used, for example road side bombs, suicide bombs, blast mines and explosive formed projectiles (Ramasamy et al 2009). These explosive weapons can cause devastating injuries. In some cases a limb or limbs may be lost at the site of the injury. If not, but where limb salvage is contra-indicated, the decision to amputate will be taken. In such situations the priority is to preserve life and stabilise the patient's condition (Ramasamy et al 2009).

While compromise to the circulation of the extremities accounts for the majority of amputations in the UK year on year, referrals to prosthetic services in the UK can result from a number of other reasons. For example, rarer cases include congenital limb deficiency where the patient is born missing a portion of a limb or limbs. This can occur if a baby simply does not fully develop or when the amputation of a forming limb occurs *in utero* when fibrous amniotic bands arising from a rupture in the amniotic sac encircle a part of the foetus. As the foetus grows and the bands do not, the resulting restricted blood flow distal to the band can, in some cases, result in the loss of that portion of the limb. This is known as amniotic band syndrome (Rushton 1983). Congenital deformity relates to a deformity of a limb at birth with, for example, fibular hemimelia, characterised by a congenital absence or shortening of the fibula resulting in associated shortening of the tibia and femoral segments and antero-medial bowing of the tibia and, foot deformities (Achterman and Kalamchi 1979). Fibular hemimelia can be treated with a series of complicated and expensive leg lengthening surgeries and repeated osteotomies, an option which is associated with continued deformity of the limb (Eze et al 2007). Alternatively, early amputation of the foot can be carried out with subsequent prosthetic rehabilitation (Naudie et al 1997). Amputation is also indicated in some cases of bone infection as well as tumours with bony involvement. Patients who have suffered severe brachial plexus injury resulting in 'flail arm', characterised by a total lack of function in the affected limb, may be given the option of amputation in order to increase functionality.

2.1.1.1 Amputation levels

If an amputation is planned then the amputation level is decided by the amputating surgeon prior to surgery, see Figure 1. The level chosen will depend on the viability of the limb; tests are carried out to assess the limb including circulation, level of infection if present and, the desired level of post-operative functionality. Extensive clinical experience has shown that below knee (transtibial) amputees functionally outperform those with an above knee (transfemoral) amputation. Surgeons considering the patients morbidity are more likely to amputate the limb more proximally whereas those who seek to maintain as much of the patients function as possible are seen to amputate more distally (Waters et al 1976). The aim is to preserve as much of the limb as possible while amputating at a suitably proximal point so that only healthy tissue remains. If this is not achieved there is a much higher chance of infection of the wound which can prevent healing and increase the probability of revision surgery at a higher level at a subsequent date. The higher the amputation the more traumatic this is for the body's systems.

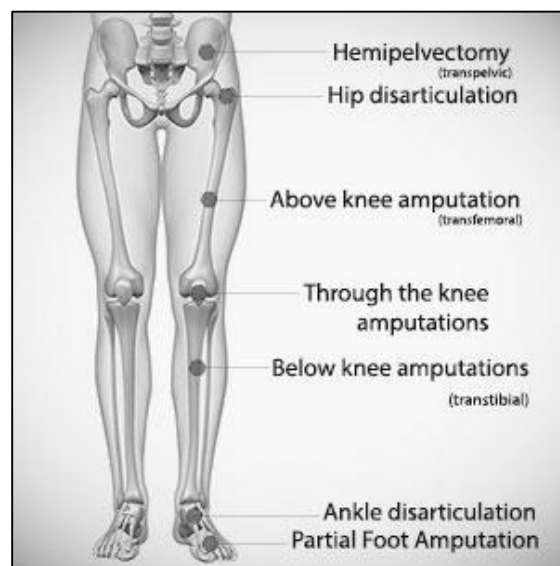


Figure 1: Levels of lower extremity amputation
(<http://www.cpousa.com/prosthetics/lower-extremity/>, no date)

Ambulation with a prosthesis has, in itself, been linked to an increase in energy expenditure (Huang et al 1979; Waters et al 1976). In addition, walking with a prosthesis with more proximal levels of amputation, e.g. at the transfemoral level, has been found to be less energy efficient than walking with a transtibial prosthesis (Waters and Mulroy 1999). Further research has linked other aspects beyond the level of amputation to energy consumption during walking for amputees, including socket shape in transfemoral amputees (Gailey et al 1993) and component alignment (Schmalz et al 2002).

2.1.2 Social and Psychological Effects of Amputation

Amputation has been associated with social and psychological effects including depression, anxiety, grief, anger and guilt (Kashani et al 1983; Marshall et al 1992; Williamson et al 1994). For those who lose a limb as a result of trauma there is a very different picture both clinically and psychologically compared to vascular or elective amputees. In contrast to amputation for chronic disease, decisions about surgery must be made quickly and these patients typically will have had no time to adjust before undergoing the surgery which resulted in the amputation. This group of amputees may have experienced multiple limb loss and sudden trauma which is likely to increase their susceptibility to psychological morbidity (Rosenfeld and Ford 2010). Research has shown that patients who have experienced accidental or traumatic amputation are more likely to develop symptoms of Post-Traumatic Stress Disorder (PTSD) than those undergoing planned amputations (Cheung et al 2003). This also appears to be the case for younger patients; Phelps et al (2008) found that a younger age at the time of amputation, regardless of cause, was associated with a greater PTSD symptom severity than that of older amputees. Further, it has been found that the majority of service amputees are not able to continue with their career in the services (Stinner et al 2010). This is in contrast to earlier times in the British military when injured soldiers were more likely to be reassigned to non-combat duties to allow them to remain in the Armed Forces. However, the sustained conflicts in Iraq and Afghanistan required that all serving soldiers were readily deployable to combat roles. This meant that if someone was to remain in military service they had to be able to fulfil the duties for which they were employed prior to injury. Therefore, if this is no longer possible, the military considers that, in order to maintain their fighting capacity on military operations, those who are unable to fight must be medically discharged (personal communication). This means that, in addition to recovery from major traumatic injury, most of these amputees will face an unanticipated life course change and will be required to make important quality of life decisions, considering what they want to achieve and what they may be able to achieve in the future.

Veterans have long been associated with an increased incidence of mental health issues. A literature review published as part of a report by Kings College London highlighted that most of the research to date into the mental health and social problems of veterans focussed on the US and that more work was needed to understand these issues among UK veterans (Dandeker et al 2003). A further review (published in 2009) assessed research published since 2003 on the welfare and health of veterans in the UK. It reported that while the mental health of the veteran population was generally comparable to the wider population, those veterans from Iraq and Afghanistan conflicts had a heavier drinking rate. It also highlighted that those with pre-service vulnerabilities, exposed to high levels of combat, and reservists

after deployment to Iraq or Afghanistan, were more likely to sustain adverse mental health outcomes (Fear et al 2009). Research published in 2011 showed that exposure to combat and trauma on deployment to Iraq and Afghanistan could lead to an increase in violence among military personnel on return to the UK (MacManus et al 2012). These risks, coupled with life changing injuries, mean that war injured personnel's rehabilitation process will be quite different from that experienced by civilian amputees.

The military provides rehabilitation for their injured personnel which aims, as much as possible, to try to restore them to their pre-injury fitness and functional levels. An additional goal of rehabilitation after amputation is to return them to a high level of quality of life (QOL) but little research has been carried out into what factors are associated with QOL among veterans. One study from the US comparing quality of life in Vietnam veterans and veterans from the conflicts in Iraq and Afghanistan found that satisfaction with prostheses is associated with increased overall QOL. Additionally, that injury to the non-amputated limb and combat associated head injury decreased satisfaction. They concluded that increased satisfaction with their prostheses combined with better mental health care and increased treatment for associated combat injuries should contribute to improvement in QOL (Epstein et al 2010).

2.2 Amputation as a result of conflict and its impact on the NHS

Conflict has long been associated with amputation, playing a major contributing role in the incidence of amputation within the younger age groups. In the past, such conflict related amputations were associated with high levels of morbidity. Major improvements in body armour and trauma medicine throughout the conflicts in Iraq and Afghanistan have led to a steady increase of 'unexpected survivors' resulting in more survivors with severe traumatic injuries including amputation. The prosthetic issues described above are increased in the population of soldiers who have lost limbs in combat and bombing as this will often have resulted in multiple complex injuries being sustained. While the number of UK servicemen affected by limb loss may superficially appear small, the most recent figures show that 214 amputees have been discharged from the military between 2001 and 2015 (Ministry of Defence 2015a). Compared to the overall numbers of people affected by traumatic amputation in the United Kingdom this constitutes a significant additional population.

Although these are small numbers, because military amputees are young, they are likely to require prosthetic care for 60 years or more. Up until around 2010, the numbers of military amputees re-joining NHS care were small. However, this number is set to rise for years to come as discussed in section 2.1. Concerns have been expressed about the impact of these

discharged veteran amputees on NHS prosthetic budgets. The majority of recent service related amputations have occurred from 2007 onwards during the height of operations in Afghanistan. Coupled with recent cuts in military budgets, it was intimated that there would be a substantial increase in the numbers of military amputees joining the NHS. How this crossover of care would be handled, was and continues to be a subject of debate. In response the UK Government launched a review of prosthetic care for veterans in the UK in January 2011. This report was accepted by Government and published in October 2011 (Murrison 2011). This review is discussed in more detail in 3.3.3.3.

2.2.1 Complications in military amputees

The clinical needs of this patient population are quite specific to this group. As discussed previously, there is a prevalence of blast injuries among injured military personnel from recent conflicts. Patients who have been involved in an explosion usually have multiple injuries so, as a result, can be described as having multidimensional injuries for which a taxonomy has been developed to understand these complex injuries (Wolf et al 2009). Blast injuries can include multiple limb loss, severe damage to the non-amputated limb, brain injury, loss of sight and damage to the abdominal organs in addition to other physical and mental comorbidity (Howe 2009). Each of these can have a considerable effect on the prosthetic rehabilitation which these patients require. If a lot of damage has been sustained by the remaining soft tissue of the residual limb then this can result in scar tissue which can be susceptible to breakdown on weight bearing with the prosthesis. Similarly, if the limb has been lost at the site of injury, the length of the residuum may not be optimal for prosthetic fitting creating difficulty with suspension of the prosthetic limb or excess pressure exerted due to the lack of surface area for the socket to load onto the residuum. Blast injuries often result in foreign objects such as shrapnel, soil and material being forced into the wound causing further damage. The presence of these contaminants often means that, in order to prevent infection, significant amounts of tissue must be removed leaving a much shorter residuum than the initial injury would have indicated. With the presence of these types of significant comorbidities it is likely that there will be a delay in prosthetic fitting and with the high incidence of double and triple amputees, rehabilitation can be a very protracted process.

2.3 Prosthetics

2.3.1 History of prosthetics

Evidence of the existence of prostheses has been found as far back as ancient Egypt (Norton 2007). Even at this point, prostheses were designed to help function, cosmesis and the patient's feeling of wholeness; Egyptian civilisations believed that the loss of the limb would

not only affect the patient in life but also in the afterlife. Providing prostheses, even only for burial purposes to make the deceased 'whole' again, was thought to ensure that they would also be 'whole' in the afterlife (Filer 1995). Prostheses which could truly be characterised as rehabilitation aids are identified in Greek and Roman civilisations where prostheses dated from 300 BC were excavated in 1858 in Italy made from copper and wood (Thurston 2007). Written accounts of the use of prostheses did not appear until later. An account of General Marcus Sergius of Rome reported that he was provided with an iron hand to enable him to return to battle and use a shield, this was considered to be 'an expensive rarity' at a time when even lower limb replacements were rare and the majority of amputees who had lost the foot or leg would use a substitute such as sticks or an adapted crutch (Kirkup 2007a).

2.3.2 Connection between the military and prosthetics

The connection between the military and prosthetic advancement is evident throughout history, arising from the use of prosthetics to enable an amputee to return to battle (Thurston 2007). Since then, advances in prosthetic technology and military have been inextricably linked. Wars create an increase in young fit amputees who want to get on with their lives and this in turn sparked prosthetic advances to allow them to do that with the best of available technology (Smith et al 2004). It was during World War II that the first prosthetic research laboratories were established. These ultimately resulted in the creation of improved socket design and hydraulic knee joints. It was also around this time that prosthetic manufacturers started to borrow technologies from military aircraft design for prosthetic advancement (Harvey et al 2012).

2.4 Prosthetic care in the UK

Prosthetics sits awkwardly within the usual structure of care provision within the NHS. Historically, all prosthetic care was provided through a system of contracts between the NHS and private companies who would employ their own staff and be responsible for the procurement of prosthetic components. Forty-four DSCs throughout the UK provide current NHS prosthetic services. In the past each of these sites would use prosthetic contractors to provide the service with contracts being renewed or put out to tender at between three and five year intervals. More recently some moves have been made by the NHS towards bringing more of their prosthetic services in-house. This means that in some DSCs the prosthetists and technicians providing the service will be employed directly by the NHS instead of by a prosthetic contractor. Over the last fifteen years Scotland have brought all five of their DSCs in house, this process was completed in late 2009, it was hoped that this would allow a degree of standardisation of care delivery throughout Scotland. This is also the case for a minority of

DSCs in England, however, the remainder of DSCs prosthetic services are still contracted out to a number of different private prosthetic companies operating in the UK. It has been suggested that this may lead to inequalities of service in different locations by different prosthetic care providers. These contracted services are similar to the contract within the DMRS at Headley Court. Blatchford, who currently holds the prosthetic contract at Headley Court, also provides prosthetic services at thirteen DSCs in England. Budgets for each individual DSC vary depending on the size of the Primary Care Trust (PCT), the perceived importance of prosthetics in the wider scheme of healthcare and the size and demographics of the prosthetic population to name a few. The three centres which serve Northern Ireland and Wales work on the contracted model of service.

During the period that they remain in military service, these patients are provided with prostheses and rehabilitation by the Ministry of Defence (MOD) and this is, anecdotally, considered to be a very high standard of care. However, once discharged from the services their prosthetic care becomes the responsibility of the NHS which has, typically, considerably less resources available for prosthetic services than the MOD. With reported initial costs per patient being £20,000 at the Defence Medical Rehabilitation Centre (DMRC) compared to only £900 in the NHS (Murrison 2011), it is clear that there is the potential for discrepancy in care provision when moving from one model of care to the other.

2.4.1 Elective and non-elective amputation

As discussed previously in the majority of cases in the UK amputation is undertaken as a treatment option for the complications of peripheral vascular disease (PVD) often associated with *diabetes mellitus*. The vascular compromise seen in cases of PVD can result in gangrene and infection that require amputation of the affected limb. The patient and their family should be made aware that the decision to amputate has been taken as a treatment option alongside others, such as various methods of limb salvage. The patient and family should be kept informed of the process of decision making which has resulted in amputation (Smith et al 2004).

Patients undergoing amputation as a result of trauma are in the minority. Limbs may be lost at the time of the injury 'traumatic amputation' or removed immediately if the limb is considered to be non-viable by the operating surgeon. In some cases amputation is carried out a significant amount of time after the initial trauma has occurred. In these cases of delayed amputation the amputation can follow a period of limb salvage. As the name suggests limb salvage incorporates a variety of methods used to maintain the injured extremity instead of amputating. In cases where all avenues of limb salvage have been exhausted the patient will

be given the treatment option of amputation; sometimes the patient may choose amputation even when there are further limb salvage treatment options still available. This can be due to extended periods of immobility, pain, discomfort and can sometimes be associated with depression linked to chronic disease. In these cases the patient elects to have the limb amputated with the desire to improve their quality of life. Where the patient has taken part in the decision to have an amputation this is described as 'elective amputation'. The pathway of care for patients undergoing elective amputation in the NHS can be found in Figure 2. This diagram illustrates that amputees can access care through their DSC throughout the process of pre-amputation, pre-prosthetic rehabilitation, primary prosthetic rehabilitation and throughout the rest of their lives whether they continue to be a prosthetic limb wearer or not. Similarly patients who do not wish to be fitted with a prosthetic limb or who are not suitable for prosthetic rehabilitation are able to access the DSC for review for the remainder of their lives.

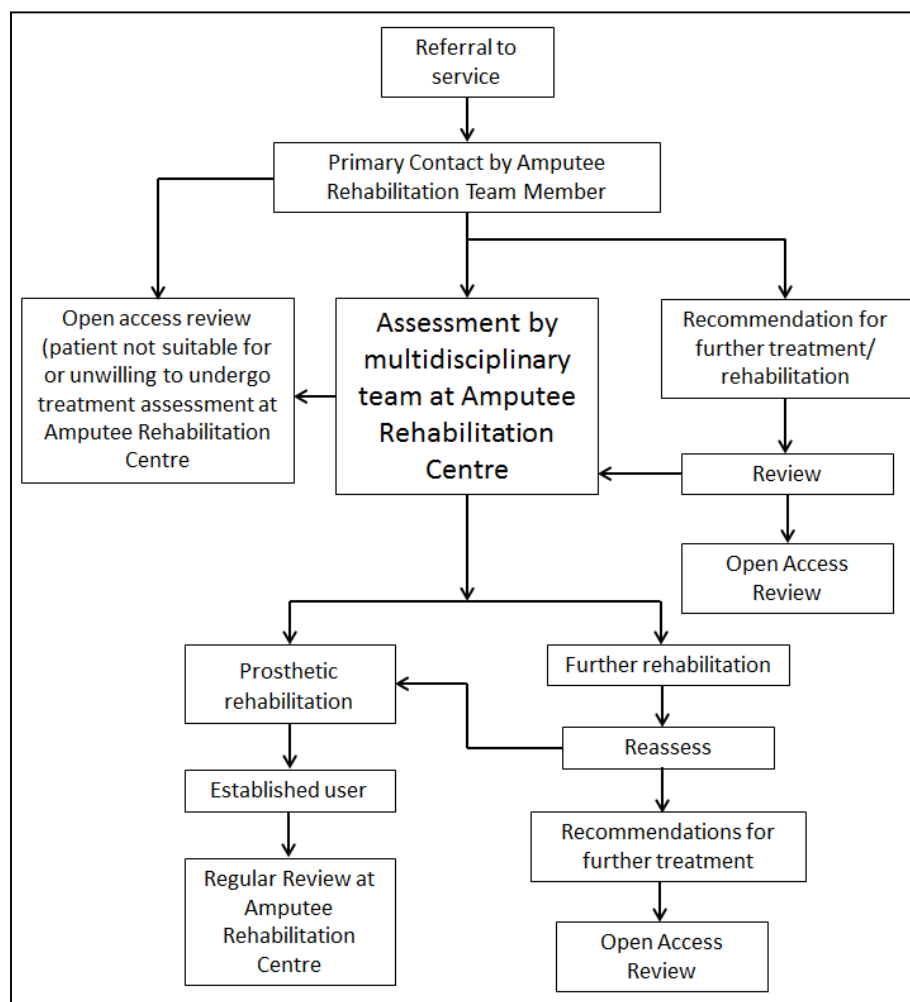


Figure 2: Care pathway for amputee rehabilitation in the NHS (British Society of Rehabilitation Medicine 2003)

2.4.2 To fit or not to fit

The distribution of DSCs in the UK does not match that of Local Health Authorities due to the relatively small number of new amputee patients per year. Less centres mean a 'critical mass' of expertise in prosthetic rehabilitation for standards of care requires to be maintained. For this reason amputations will not always be undertaken at hospitals hosting a DSC, in fact the majority are not. Formal referral therefore requires to be made by the amputating hospital to the local DSC. All amputees should be offered a referral to the DSC even if the decision has already been made before discharge from the amputating hospital that the patient will not be fitted with a functional prosthetic limb. This can be attributed to the fact that, for some amputees, the aim of rehabilitation within the DSC is to enable them to remain independent without prostheses. This rehabilitation is offered within the DSC as the multidisciplinary team based there are experienced in rehabilitating amputees. This expertise is unlikely to be found outwith the DSCs due to the specialised needs of this group of patients.

It is hard to know what the ratio of amputees not fitted with a prosthesis is compared to those who are, as collated figures only relate to the number of patients referred to the DSCs, not how many actually complete rehabilitation with a functional prosthetic device. Before a referral has been made to the DSC the patient will undergo a consultation in which their suitability for prosthetic rehabilitation will be assessed. This assessment can take place at the amputating hospital or at the DSC depending on the patient's general post-operative status.

Not all patients who have undergone amputation will be fitted with a prosthesis. If the decision is taken not to go ahead with prosthetic rehabilitation before the amputation has been carried out then, in some cases, this can have an influence of the level of amputation. For example, for prosthetic fitting, knee disarticulation can cause difficulties in accommodating components. The length of the residual limb can mean that prosthetic knee joint is not at the same level as the remaining healthy knee joint on the contralateral side. When the patient is sitting this discrepancy in knee joint centre levels results in an asymmetry which patients can find unacceptable. However, when thinking about patients who will be non-ambulatory, this level of amputation can provide a very stable stump for balance while sitting and during transfers. In sedentary patients this amputation level avoids knee flexion contractures seen in patients with a below knee amputation and asymmetry during sitting which can lead to back problems in patients who have undergone transfemoral amputation with a view to being prosthetically rehabilitated.

2.4.3 Prosthetic Rehabilitation

When the decision is taken to prosthetically rehabilitate a patient, this sets in motion a process which will see the patient through from pre-prosthetic rehabilitation to discharge with a functional prosthetic limb. The stage at which the prosthetist would first meet the patient is generally when they have been admitted as an inpatient to the hospital hosting the DSC. A multidisciplinary ward round is carried out of all amputee patients on the designated rehabilitation ward. The prosthetist taking part in that ward round is not necessarily the prosthetists that will be treating all of those patients, patients are allocated to prosthetists on a case by case basis depending on the current patient load of each prosthetist.

The first stage of this process, pre-prosthetic rehabilitation (following on from a pre amputation therapy programme in elective amputees), involves daily sessions of intensive therapy provided by physiotherapists who are expert in the requirements of amputees. These sessions focus on the core strength of the patient. In part this is due to the fact that patients will be required to use their upper body strengths for moving themselves while they are not wearing the limb. It is also key as patients need a certain level of upper body strength to don and doff a prosthesis. Physiotherapy at this stage can also aid in the reduction or prevention of hip and knee flexion contractures which can arise and hinder the fitting of prosthetic devices. Finally, physiotherapists will be able to introduce early walking aids (EWA) to the patient, such as the PAM aid for below knee amputees and femurette for above knee amputees. This early mobilisation can greatly increase the success of prosthetic rehabilitation and in some cases can provide an indication to physiotherapists of the suitability of certain patients for definitive prosthetic fitting.

The first step in the process of supplying a prosthetic limb is to take a cast of the residual limb, this can be achieved by taking a negative plaster cast model of the stump or, computer software (CAD/CAM) can be used to capture the shape and volume of the residual limb. A positive model of the stump is then made using the cast. This positive model then undergoes a process call 'rectification' by the prosthetist. During rectification, the prosthetist aims to pre load certain areas of the stump and relieve other areas of the stump such as the end or any bony prominences which are unable to withstand the application of excess pressures without leading to primarily pain and skin breakdown during limb wearing. This rectified positive model of the stump is then used to fabricate a bespoke prosthetic socket which acts as the starting point around which the rest of the prosthetic limb is to be assembled. When the whole limb has been assembled the prosthetist will 'bench align' the prosthesis, this process gives the prosthetist a chance to check the safety of the limb before trying it on the patient as well as beginning the process of alignment once the patients shoe has been put onto the prosthesis. The pitch of the shoe can have a large impact on the alignment and therefore safety of the

limb if not set correctly at this stage. The prosthesis can then be fitted to the patient. At this stage the prosthetists usually has to make a series of minor adjustments to the fit of the socket and the alignment of the limb in order to allow the patient to comfortably wear the limb. The adjustments to the alignment of the prosthetic limb are concerned with creating a stable limb as well as minimising gait deviations associated with a prosthetic limb which is not optimally aligned. Patients can quickly develop gait deviations if the prosthetic limb is not aligned correctly so it is important to eradicate these as much as possible in the early rehabilitation stages. Once the patient can comfortably wear the limb and the prosthetist is satisfied that the limb is optimally aligned, the patient can begin gait training which they will then continue throughout their rehabilitation, under the care of the physiotherapy team.

2.4.4 Prosthetic Treatment Episodes

Amputees can be patients for many years; however, from a management point of view, they cannot remain as constantly open cases within each DSC. In order to cope with this prosthetic care is delivered in treatment episodes. Primary patients undergo a series of reviews at designated time points during their first year after initial prosthetic rehabilitation. These reviews allow the prosthetist to assess the fit of the prosthetic limb; during the first few months of prosthetic use it is expected that the shape and volume of the stump will change considerably. Once this has occurred the patient requires to be recast and a new socket fitted to the prosthesis. After the first year of limb wearing the patient will be classed as an established amputee and reviewed less frequently. In the past, patients would have been allocated review appointments. Now, largely, (particularly in the Scottish centres) established amputees are only reviewed on a yearly basis and otherwise will only attend the prosthetic clinic upon request. Each time the patient attends the clinic for maintenance or review a new treatment episode is opened for them and remains open until any required work has been completed. Patients need to be aware that they are able to contact the DSC whenever required and, in cases needing repairs, they must be given an appointment within a set period of time.

3 Chapter 3 – Scoping Study

Much of the available prosthetics research relates to developing the functional capabilities and fit of prosthetic components. Significant advances have been made in these areas over the last century and particularly over the last thirty years. These advances can be attributed to efforts from multiple disciplines responding to the needs of active military personnel and veterans (Laferrier and Gailey 2010). Despite advances in prosthetic technology, determining what components are best for each patient is not a simple decision. While it is tempting to imagine that the most advanced and expensive components will always be the correct choice this is not always the case (Laferrier and Gailey 2010). However, there is a lack of research of effectiveness or experience of different prosthesis on which to base decisions. The decision is the remit of the prosthetic rehabilitation team.

3.1.1 Rationale

Due to the lack of existing research a scoping study was undertaken to inform the development of the main research project. The scoping study was undertaken in three stages. Stage one consisted of a literature search to identify relevant research literature; stage two, a search and summary of relevant policy documents and stage three, interviews and discussion with key stakeholders. These three elements were undertaken concurrently which meant that each stage was informed throughout the process by the findings of the other two stages. The stages are described in a linear way for clarity. After all three stages were complete the research questions and aims of the PhD project were finalised.

3.1.2 Aim

The aims of the scoping study were:-

1. To review relevant research literature on decision making in prosthetic prescription; both clinician and patient based. [stage 1] (Figure 3)
2. To identify policy documents pertinent to the delivery of prosthetic care in the UK for civilian and military amputees [stage 2] (Figure 3).
3. To identify the pathways of care in both the MOD and the NHS for traumatic amputees [stage 2&3] (Figure 3)
4. To explore the relevance of the proposed research topic for those involved in prosthetic care delivery in the MOD and the NHS [stage 3] (Figure 3)

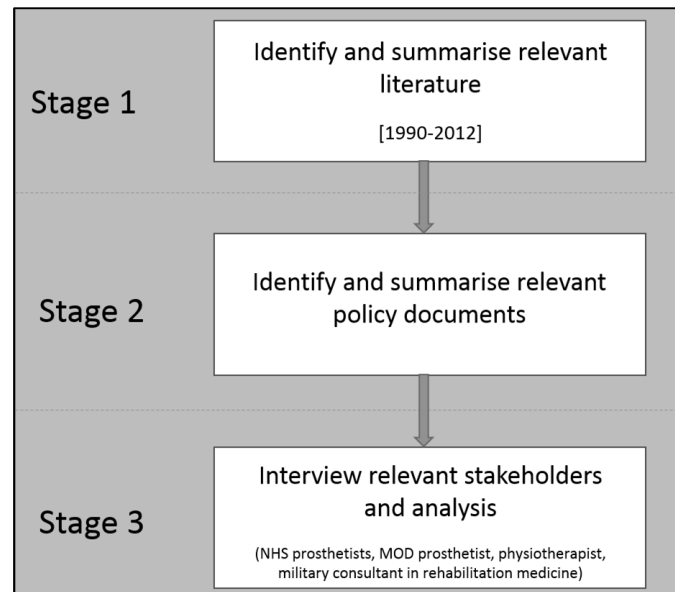


Figure 3: Scoping study stages

3.2 Literature review

3.2.1 Aim

The aim of the literature review was to identify and review qualitative or quantitative empirical studies or literature reviews that had investigated clinician and/or patient decision making in prosthetic prescription in an applied setting.

3.2.1.1 Selection Criteria

In order to be eligible for inclusion the literature had to meet the criteria outlined in Table 1 below.

Table 1: Selection criteria

Inclusion criteria	Exclusion criteria
Participants – <ul style="list-style-type: none"> adults (18+ years of age) with upper or lower limb amputation (defined as level of amputation, partial foot or more proximal and partial hand and more proximal) Prosthetists/clinicians involved in prosthetic prescription 	Expert opinion or commentaries
Empirical studies	Studies of non-limb prosthetics (cardiac, dental, aural, optical, implant, replacement joint, neural)
Literature reviews of empirical studies	Research focussed on the decision of whether or not to amputate

Publications available in English	Phantom limb pain
Year limitations – 1990-2012	
Peer-review publication	

3.2.2 Search strategy

The following electronic databases were searched

- CINAHL (January 1990 - March 2012)
- MEDLINE (January 1990 - March 2012)
- PsychINFO (January 1990 – March 2012)

These three databases were selected following consultation with my supervisors because they collectively offered the potential for the widest coverage of the prosthetics literature. For example; MEDLINE is the largest clinical electronic database available, covering large areas of research, including sociological literature on healthcare experience (patient and professional). The two largest international prosthetics journals (The Journal of Prosthetics and Orthotics and Prosthetics and Orthotics International) are indexed to CINAHL. PsychINFO was selected because of its coverage of the literature on psychology within healthcare thus including research on decision making in healthcare settings.

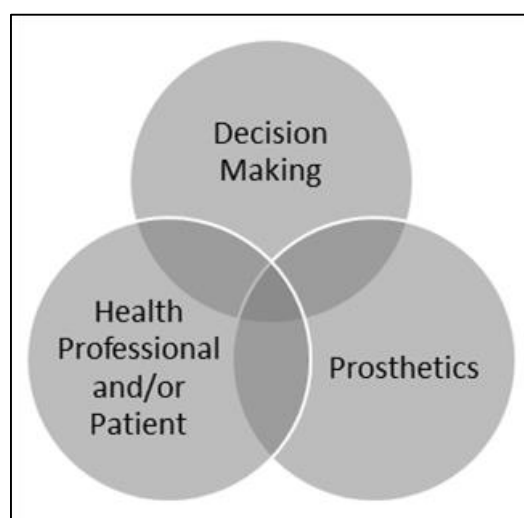


Figure 4: Literature of interest

An initial search strategy was constructed. These included terms were developed by brainstorming around the three areas of interest as outlined in Figure 4, incorporating terms relating to choice in prescription and terms relating to prosthetics. The search strategy was then run through the shared platform EBSCOhost which performed the search across the

three chosen electronic databases. The search used key headings linked with Boolean terms (AND, OR, NOT) to increase specificity. Truncation was used to incorporate different spellings relating to prosthetics and amputation. Prosthetics is not a word which is specific to artificial limbs but prevalent in other fields, particularly dentistry, for this reason I attempted to reduce the amount of included literature relating to dentistry. This was done by using the Boolean term NOT for dent* and dental. This search strategy was designed to identify what work had been undertaken in this field to inform the key research question and future work.

Table 2: Search strategy

Search Number	Search terms
S1	Consumer decision making OR patient decision making OR decision making OR clinician decision making OR clinical decision making OR treatment choice OR prescription choice
S2	Prosthetics OR prostheses OR prosthesis OR artificial limb OR amputation OR amputee OR limb loss OR prosth* OR amput*
S3	S1 AND S2
S4	S3 NOT dent* NOT dental

3.2.3 Strategy for data synthesis

To extract the following data from the included papers and collate it in a table:

- Study aim
- Number of participants
- Sample demographics
- Type of prosthetics
- Study design
- Outcome measures
- Findings

To use this table to synthesise the data from the included papers using a narrative summary. To draw conclusions from their findings and consider their recommendations for future research.

3.2.4 Search results

My search identified 566 possible records. After removing duplications there were 535 remaining records. I screened the titles of these 535 records, during this process I eliminated

528 irrelevant records (See Figure 5). The abstracts of the remaining seven papers were obtained and the inclusion and exclusion criteria applied. I excluded four further papers at this stage. The full texts of the remaining three papers were then obtained.

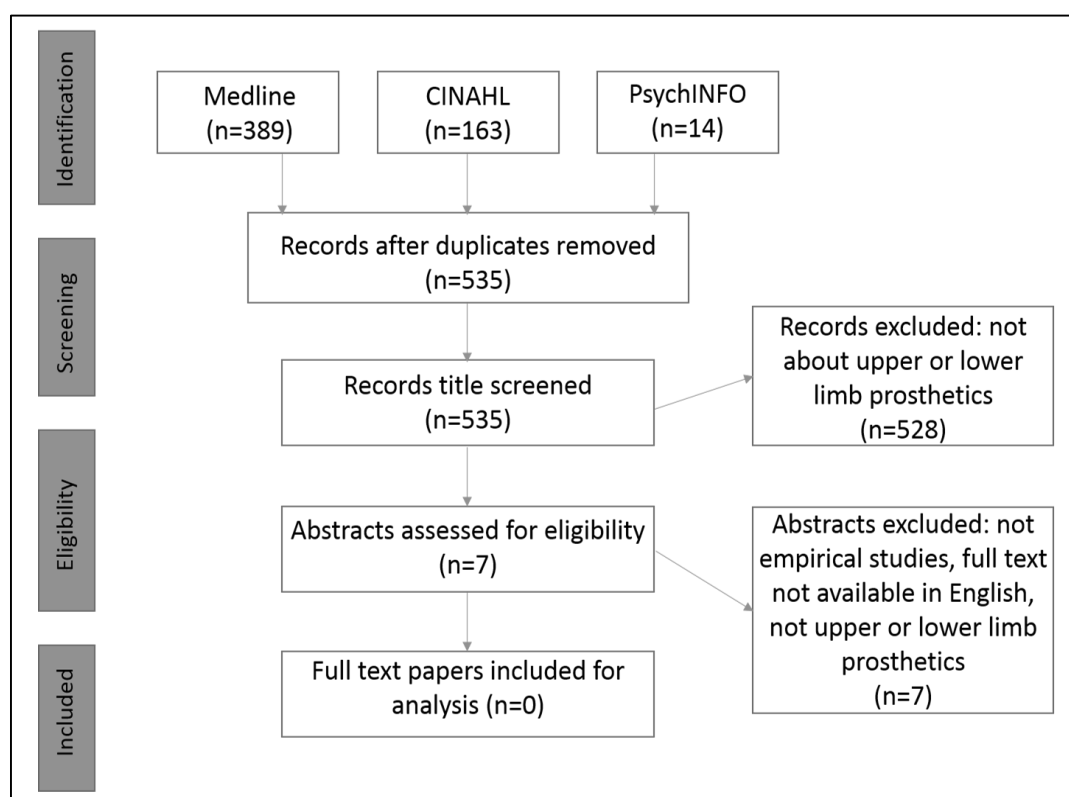


Figure 5: Study flow diagram

Table 3: Papers excluded at abstract level

Authors	Title	Journal Title	Reason for exclusion
(Kahle and Highsmith 2009)	Evidence-based practice for the individual with amputation	inMotion	Non peer reviewed
(Nelson et al 2006)	Limb deficiency and prosthetic management. 1. Decision making in prosthetic prescription and management	Archives of Physical Medicine and Rehabilitation	Commentary
(Pibarot and Dumesnil 2006)	Prosthesis-patient mismatch: definition, clinical impact, and prevention	Heart	Not related to limb prosthetics
(Welraeds 1998)	The rehabilitation of elderly amputees	Revue Médicale de Bruxelles	Not available in English

The final three papers were rejected from inclusion after the full text for each had been obtained. Marzoug et al (2003) carried out a study which aimed to develop a practical assessment tool for amputees who were considered doubtful for long term prosthesis use. This study was excluded at this stage as their focus was the decision to prescribe a prosthesis or not to these patients and not what actual prosthetic prescription would be. A further study was excluded as it was found at the full text stage that it was not a review or a piece of empirical research (Uustal 2009). The final paper was a review of rehabilitation of following traumatic lower limb amputation by Jelic and Eldar (2003). The methods of this review were not made explicit in the paper. There was no detail provided on the process of identifying papers for review. They stated that they were reporting on the findings of one hundred and fourteen 'pertinent reports' published from 1975 onwards in relation to the rehabilitation process and its effectiveness in major traumatic lower limb amputations. Due to the lack of methodological rigour this review was also excluded. At the end of this process I had identified no literature on which to base the prospective research project.

3.2.5 Ongoing literature searches

During the course of my PhD I continued to read on the topics of patient involvement in prosthetic care and decision making in prosthetic prescription. I reran the initial search several times throughout my PhD as well as hand searching the reference lists of relevant research papers. It became clear that the area of prosthetic prescription was growing and that there was more exploration of patients' perspectives of prosthetic care. Through rerunning the initial search I identified twenty relevant papers, a narrative review of these papers can be found below. Some of this literature was published during the time frame of my original literature search but was not identified using my search strategy and the remainder of the papers were published after I had undertaken my initial literature review.

The literature identified a growing interest in issues relating to prosthetic prescription and the patients' perspective of their prostheses and prosthetic care. Thinking about the users of technology such as prosthetic devices is something that has more recently been considered as an area of interest. In their book chapter which considered understanding the users of technology Brown-Triolo (2002, p31) states that "Only since researchers began to focus on the reason for abandonment of technology have they looked beyond the technology to the users." The focus of this chapter was on the use of assistive technology (AT), a category which prostheses are part of.

Several studies have explored patients' satisfaction with their prostheses and their prosthetic care. One qualitative study which explored patients' adjustment to prostheses found that satisfaction with a prosthesis was dependent on the how well its capabilities were aligned with

their expectations of what could be achieved (Gallagher and Maclachlan 2001). They highlighted from this study the importance of establishing the limb wearer's expectations when assessing prosthetic outcome. Satisfaction with prostheses was also seen to be linked to communication between prosthetists and their patients. In an unpublished Doctoral thesis Gravelle (2003) investigated the factors affecting patients' prosthetic satisfaction, they identified that clinician-patient communication had a bigger impact on satisfaction than fit, comfort and practicality.

Two further studies reported more generally on satisfaction among lower limb amputees. Dillingham et al (2001) carried out a study with 78 participants with trauma related amputations in the US which aimed to document and examine their use, satisfaction and issues with their prostheses. They only reported generally about participants' satisfaction with services, reporting that 60% had indicated that they were satisfied with other characteristics of their prostheses including, weight, appearance, prosthetic services and ease of use. In addition they noted that despite finding high levels of prosthetic use among their participants only 43% reported being satisfied with prosthetic comfort. They also found that issues of phantom pain and residual limb skin conditions were common problems in this group. A study using questionnaire methods was conducted by Gailey et al (2010) to compare the functional outcomes of US service members with lower limb amputations from OIF/OEF (Operation Iraqi Freedom/Operation Enduring Freedom) and the Vietnam war, 283 and 298 participants respectively. Participants ranked their satisfaction with their current prosthesis and both groups reported similar levels of satisfaction. They reported that they had found comparable levels of satisfaction with prostheses as was found by Dillingham (2001).

Further studies identified the importance of communication in the prosthetist patient encounter (Pezzin et al 2004; Berke et al 2010). Pezzin et al (2004) conducted a retrospective cohort study of people who had undergone amputation. Using telephone survey methods they gathered data from 935 people with major amputations due to diabetes, vascular disease, trauma or malignancy. They found that a significant number of participants reported negative perceptions of their prosthetists interpersonal skills, with about 15% reporting that they felt their prosthetist was 'in a hurry', 'did not explain' and 'does not discuss'. They concluded that poor communication could be linked to dissatisfaction with their prosthetic device (Pezzin et al 2004). Van der Linde et al (2007) used the QUOTE questionnaire (Quality of care through the patient's eyes) as part of a larger programme of research aimed at producing national guidelines for lower limb prosthetic prescription in the Netherlands. Findings from this part of the programme showed a discrepancy between the patients' expectations of their interaction with the clinician and their actual experience, leading to feelings of dissatisfaction. Communication was again cited as an area for improvement by Berke et al (2010) who

suggested that for more successful prosthetic outcomes to be achieved clinical factors must be combined with patients' goals and desires during the prosthetic prescription process. Schaffalitzky et al (2009) used the repertory grid technique in a case study series to identify the values and preferences of prosthetic users. Findings indicated that what prosthetic users from the same demographic wanted prosthetically varied, highlighting the individualised nature of amputees needs. They also indicated that the technological advances made within prosthetics are not necessarily appreciated by the users of that technology. Linked to the communication issues highlighted by other authors, Schaffalitzky et al (2009) indicated that their findings supported the increasing concern in prosthetic prescription about the lack of attention to patient preferences.

Murray (2013) carried out qualitative data analysis of electronic messages posted to three online discussion groups. Their aim was to explore the communication between patients and their prosthetists, difficulties and challenges they had encountered and how some of these issues were overcome. The data from all three groups was brought together and analysed using thematic analysis. One of the themes focussed on the need to communicate well with their prosthetist. The findings under this theme highlighted the growing relationship between patients and prosthetists over time and the positive experiences resulting from the development of effective communication. They also identified patients' desire for more effective working between members of their healthcare teams. An area of future research they identified was on the implementation of a patient centred approach within prosthetic care. Their findings indicated that it was not a reluctance on the part of prosthetists to work in this way but issues around the implementation of this type of approach that needed more attention. The findings of a later metasynthesis exploring the experience of prosthesis use by the same author suggested that changes were needed in the design and organisation of rehabilitation health services (Murray and Forshaw 2013). Their recommended changes included greater use of pre and post-operative psychoeducation in the rehabilitation of this group, the use of psychotherapy to help develop and support coping strategies as well as providing peer support from patients further through their rehabilitation process who had made positive adjustments to amputation and prosthesis use.

One small study focussed on the preferences of women with major limb amputations for rehabilitation services (Elnitsky et al 2013). They used a convenience sample of five veteran and non-veteran women (between both groups) with major limb amputations who participated in a panel interview at a regional Veterans Affairs Prosthetics Conference. The findings showed that for these women privacy and dignity were among their primary concerns. In addition they reported that patient centred choices were restricted and that important decisions

were made without consulting patients. As a result of this lack of involvement these women were provided with limbs that were too heavy and too large.

The process of prosthetic prescription is an issue which has been debated in the literature with a number of different approaches taken to research in this area. Van der Linde et al carried out a series of studies with the aim of developing guidelines for prosthetic prescription in the Netherlands (Van der Linde et al 2004a; Van der Linde et al 2004b; Van der Linde et al 2005; Van der Linde et al 2007). These studies included a literature review, an observational study, interviews with clinical experts, a Delphi study and finally a patient questionnaire study (discussed above). The results of the literature review, observational study and interviews with experts were used as the basis for the Delphi study to develop national clinical guidelines for the prescription of lower limb prostheses. They were unable to identify specific prescription criteria from their systematic literature review which they highlighted as a limitation in the Delphi process as there was a lack of explicit information available on prescription criteria. Through the consensus exercise they created draft clinical guidelines. The authors hoped that these draft guidelines would help to form the basis for an international discussion on prescription guidelines but noted that they would need to be measured and evaluated in the first instance. The development of prosthetic guidelines was also undertaken by other groups (RSL Steeper 2011; Geertzen et al 2015). RSL Steeper are a private prosthetic company based in the UK, they provide prosthetic services in the NHS through a number of DSCs. In 2011 they published best practice guidelines which aimed to support clinicians' decision making in prosthetic prescription. These guidelines were based on a literature review followed by an adapted form of the Delphi technique. The literature review was used to compile a list of preliminary prescription criteria used as the basis for the consensus process. All of those involved in the consensus process were prosthetists who were working for RSL Steeper at that time. When they were published these guidelines were not freely available, they had to be purchased in hard back form. Anecdotal accounts suggest that these guidelines were not widely used. Most recently Geertzen et al (2015) aimed to produce evidence based guidelines for amputation and prosthetics in the lower extremity in the Netherlands. They carried out searches across five databases. The search strategy which related to prosthetic provision aimed to find articles describing the effects of prostheses on functional outcomes in amputees. Nine articles were included for discussion, three systematic reviews and six primary studies. They highlighted that the value of the evidence was limited due to the design and size of the included studies. Their conclusions noted the lack of knowledge in prosthetic provision, the insufficient level of the evidence underlying the guidelines and that there were still many unknowns (Geertzen et al 2015).

Research has also been undertaken which aimed to identify the important outcomes of prosthetic prescription. Schaffalitzky et al (2011) undertook a series of focus groups with prosthetic service users and semi-structured interviews with service providers to explore the outcomes of prosthetic prescription. This study was carried out in the Republic of Ireland with twenty four prosthetic service users and ten service providers. Inductive thematic analysis was used to analyse the data. They found no major differences in what were seen as the main predictors and outcomes of prosthetic prescription between users and providers. The two perspectives allowed them to see the difference in the meaning of the identified outcomes. For example, independence was identified by both groups, however, the user group identified this as an emotional outcome whereas service providers saw this as a functional outcome. They concluded that their findings could be used to develop more appropriate outcome measures to evaluate future research and to better understand why and when to prescribe a prosthesis. These findings were subsequently used as the foundation of a study using the Delphi technique to develop consensus on the factors predicting prosthetic prescription and the outcomes of prosthetic prescription (Schaffalitzky et al 2012). Three rounds were undertaken in the Delphi process, by email, using a questionnaire developed from the previous research findings. Twenty one experts completed all three rounds of the Delphi. They identified nineteen predictors of prosthetic fitting and use that met consensus, of which twelve were physical and had predominantly been identified in previous research. These nineteen factors were split into age and illness predictors, physical condition predictors and psychological and social predictors. They concluded that their findings could be used in further research in a number of areas; promoting the patient-clinician interaction and standardising interventions and prosthetic components on an individual basis. They also stressed the important role that psychological factors play in prosthetic limb prescription and the possibility of improving patient satisfaction and quality of life as well as optimising the use of prosthetic technology.

Sansam et al (2014) carried out a qualitative study with doctors, prosthetists and physiotherapists with expertise in amputee rehabilitation across four DSCs in England. The aim of this study was to gain a better understanding of how professionals decided if a prosthesis should be prescribed and what components to prescribe in that situation. They identified four main themes in their analysis; estimating outcome, difficulties predicting outcome, patient choice and barriers to prescribing. In their discussion they identified that the attributes which participants identified when making their prescription decisions fitted closely with the international classification of functioning (ICF) structure but that no participants reported using this framework (World Health Organization 2002). They felt that the use of the ICF may become more explicit after future work on core sets for persons with amputation was

completed (Kohler et al 2009). They also indicated that participants described approaches to decision making in prosthetics that reflected national (British Society of Rehabilitation Medicine 2003) and international guidance (CARF International 2015) on multidisciplinary assessment for person centred care but that further observational research was required to explore this further.

3.2.6 Conclusion

The findings from the literature search undertaken at the beginning of my PhD was inconclusive as no relevant studies were identified. However, over recent years there has been increased interest and research undertaken with the aim of exploring prosthetic prescription from a number of different perspectives. From the prosthetic satisfaction literature it can be seen that there is a link between dissatisfaction with prosthetic devices and a lack of communication from the rehabilitation team. It has also been identified that a better relationship can be developed over time between prosthetists and patients to facilitate more effective working between these groups. The research which has aimed to produce evidence based guidelines for prosthetic prescription has identified that there is still a lack of good quality research evidence on which to base such guidelines. Finally, recent research has indicated that further work is needed to explore the prosthetic decision making process from the perspective of the patient in order to understand if their experience of a person-centred approach aligns with accounts given by health care professionals working in this field.

The majority of the studies which have been discussed have been conducted outwith the UK and therefor the UK NHS system of prosthetic service delivery. This includes the work which has been carried out on guideline development by several groups in the Netherlands (Van der Linde et al 2003; Van der Linde et al 2004a; Van der Linde et al 2004b; Van der Linde et al 2005; Van der Linde et al 2007; Geertzen et al 2015). While a number of these studies focussed on trauma amputee participants, both from conflict and civilian populations they too have been based outwith the UK in the United States therefore exploring prosthetic satisfaction in a different structure of prosthetic care delivery, based on a pay for service system, either by the patient themselves or through various health insurance providers (Dillingham et al 2001; Pezzin et al 2004; Berke et al 2010; Gailey et al 2010; Elnitsky et al 2013). Similarly, the work of Schaffalitzky has been undertaken in the Republic of Ireland, a service not provided on the same premise as the NHS (Schaffalitzky et al 2009; Schaffalitzky et al 2011; Schaffalitzky et al 2012). In those studies which have been carried out in the UK, none have specifically focussed on trauma amputees, either civilian or service related. The most applicable to my proposed research studies was the study by Sansam et al (2014), however, again it focussed on the decision to prescribe a prosthesis in elderly amputees.

Further research was therefore required to look more closely at the trauma amputee group in the UK.

3.3 Policy document review and analysis

3.3.1 Aim

The aim of the policy document review was to explore policy relating to prosthetic care for military amputees as well as to develop an understanding of the pathways of healthcare for seriously injured patients within the MOD and the crossover of care from the MOD to the NHS. A key aspect of this review was to understand the responsibilities of the NHS and MOD with respect to the provision of prosthetic care for servicemen and veterans.

3.3.2 Method

The review was started by conducting a general search on Google to identify broad areas to search for the reports and policy documents that would be applicable to the topic. From these initial findings, and by drawing on information from meetings with key informants, it was possible to identify where to conduct more in depth searches. Searches were then carried out on a number of websites of organisations associated with Government Policy and health care as well as the military. These included the websites of the Department of Health, NHS England, Scotland and Wales, UK Parliament, Scottish Government, the Welsh Assembly and the Ministry of Defence. The following key words were used individually or combined; veterans, prosthetics, prosthetics and veterans and amputee and veteran. A range of different documents were identified including policy documents, health circulars regarding veterans' health care needs, pledges made by successive Governments about care provision for veterans after discharge and the responsibilities of the NHS in relation to veterans. The documents included were restricted from 1997-2012 as it was felt that key information related to the years prior to the UK's involvement in Afghanistan to the present. The references of each of these documents were then hand searched to identify further documents which had not been found in the initial website searches. This strategy identified thirty one documents (See Table 4) which were then read and their key messages or recommendations summarised.

Table 4: Included policy documents

Reference	Title
Department of Health (1997)	Priority treatment of War Pensioners
Welsh Assembly Government (2003)	Priority treatment for war pensioners and the Veterans Agency – Notes about War Disablement Pensions and war Widows/Widowers Pensions
Department of Health (2005)	Health Service Guidance covering arrangements between the Ministry of Defence and the NHS
Ministry of Defence (2005)	Delivering our Armed Forces' Healthcare needs: A Concordat between the UK Departments of Health and the Ministry of Defence
The Scottish Government (2007)	A Concordat between the Scottish Ministers and the Secretary of State for Defence
Department of Health (2007)	Access to health services for military veterans
House of Commons Defence Committee (2008)	Medical Care for the Armed Forces: Seventh Report of Session 2007-08
Welsh Assembly Government (2008)	Priority Treatment and Healthcare for Veterans
Department of Health (2008)	Health Service for the Armed Forces, their families and veterans – Guidance for SHAs
Ministry of Defence (2008)	The Nation's Commitment: Cross-Government Support to our Armed Forces, their Families and Veterans
The Scottish Government (2008)	Scotland's Veterans and Forces' Communities: meeting our commitment
Morgan (2009)	Annual Report on Implementation of the Service Personnel Command Paper
External Reference Group (2009)	The Nation's Commitment: Cross-Government Support to Our Armed Forces, their Families and Veterans - External Reference Group Annual Report
Donnelley (2009)	Annual Report on Scottish Government Support for our Armed Forces and Veterans Community
O'Brien (2010)	Medical Care (Veterans)
Department of Health (2010a)	Access to health services for military veterans – priority treatment
Department of Health (2010b)	Continuing care for veterans: Note to limb centre managers, providers, service personnel & Veterans Agency, and veterans organisations.
Welsh Assembly Government (2010)	Improving care for veterans and severely injured service personnel
NHS England (2010a)	NHS Operating Framework in England 2010/2011
Leigh (2010)	Ministry of Defence: treating injury and illness arising on military operations, twenty-seventh report of session 2009-2011
Ministry of Defence (2010a)	Report of the Task Force on the Military Covenant
(NHS England 2010c)	Revision to the Operating Framework for the NHS in England 2010/2011
External Reference Group (2010)	The Nation's Commitment: Cross-Government Support to Our Armed Forces, their Families and Veterans - External Reference Group Annual Report
Ministry of Defence (2010b)	The review of the Armed Forces compensation scheme
Arbuthnot (2011)	The Armed Forces Bill: Special Reports of session 2010-2011
Ministry of Defence (2011)	The Armed Forces Covenant – Today and Tomorrow An enduring covenant between the people of the United Kingdom Her Majesty's Government – and – All those who serve or have served in the Armed Forces of the Crown and their families

NHS England (2010b)	NHS Operating Framework in England 2011/2012
Department of Health (2011)	Health Services for the Armed Forces and Veterans
Welsh Assembly Government (2011)	Military Veterans and Service-related conditions: Training on Priority Treatment and Post-Traumatic Stress Disorder
House of Commons Defence Committee (2011)	The Military Covenant in action? Part 1: military casualties
Murrison (2011)	A Better Deal for Military Amputees

3.3.3 Results

The thirty one documents that were reviewed all stemmed from the principles underpinning the Military Covenant and all have reference to it or its recommendations. The principles of the covenant have been in evidence in the UK since the time of the First World War. They embodied what the UK Government felt they owed to members of their Armed Forces, their families and veterans. The covenant originated from the policy of conscription that was implemented during the First World War to maintain the army's operations. It conveyed the sense of gratitude that the Government felt was owed to those who had served in the Armed Forces during this war. This principle of gratitude underpins the Military Covenant. Within the last decade the UK has formalised its definition of a veteran as *"all personnel who have served more than one day (and their dependents)"* (Dandeker et al 2006, p163). This is the most inclusive definition of a veteran and meant that in 2006 it was estimated that 20% of the UK's population was included when all ex-service personnel and their dependants had been taken into account (Dandeker et al 2006).

The UK military has not always had a good record of caring for its veterans (Stanhope 1979). These shortcomings have and continue to be seen in the involvement of the third sector in the care of ex-service personnel and their families. The need for an increase in the standard of care available to veterans began to be recognised in the 1970s.

"Britain's record for caring for ex-servicemen has not always been distinguished. There are those who would argue that it still falls far short of the ideal. But it is better than it was, and the man who is really down on his luck should be able to find help somewhere."

(Stanhope 1979, p281)

In response to continued criticisms of care for veterans and their dependants the Military Covenant was first formalised in writing in 2000 (Ministry of Defence 2000). This document was initially a single service covenant with a remit for the Army only. Over subsequent years

the covenant has been updated and reviewed as the above expansions to the term 'veteran' were made. In 2008 an updated version was published as the Government reaffirmed their position to support all ex-service men and women and their families (Ministry of Defence 2008).

There has not always been public support for UK involvement in conflicts and this was particularly the case in conflicts in Iraq and Afghanistan. Data was gathered about attitudes towards Britain's involvement in Afghanistan in early 2009 as part of the British Election Study Continuous Monitoring Survey (BESCMS). This part of the data was presented in a briefing paper by Scotto et al (2011) and concluded that the widespread public support of Britain's involvement in Afghanistan was decreasing quickly after seven years of conflict. However, even when support for the conflict was poor, the public's desire to support troops during wartime remained. Support for the conflict in Iraq was attributed mainly to television and broadcasting coverage from Iraq itself (Lewis 2004). Throughout these conflicts there was evidence of tension between the British military and the public and the obligations between them (McCartney 2010). In response to this tension consecutive governments renewed the Military Covenant stating their commitment of support to Armed Forces personnel, both during their time in service and beyond.

The Coalition Government who started their term in Government in 2010 continued this position of support and for the first time a tri-service covenant was produced stating the Governments commitments to all three of the Armed Forces and their veterans. The two principles of the covenant are:

- the armed forces community should not face disadvantage compared to other citizens in the provision of public and commercial services
- Special consideration is appropriate in some cases, especially for those who have given most such as the injured and the bereaved (Ministry of Defence 2015b)

While these were important steps the Government still had no legal obligation to carry out the commitments made in the covenant. At the beginning of 2011 there was much discussion and publicity surrounding the enshrinement of the covenant into law (BBC News 2011). Despite this, the only aspect of the covenant which was translated into law was the Governments requirement to report annually on how they had delivered on each point outlined in the covenant and how they could further improve in the future. These points included, healthcare, education, housing, benefits and tax, responsibility of care, deployment and support after service (Ministry of Defence 2011)

3.3.3.1 Military access to priority NHS care

Many of the reviewed policy documents from the Department of Health and the devolved administrations highlighted that members of the armed forces had priority access to the NHS. Several policy documents from government, military and the NHS discuss the access to care in the NHS for members of the armed forces, their families and veterans (Welsh Assembly Government 2003; Department of Health 2005; Department of Health 2010a). These documents highlighted that members of these groups had access to priority care within the NHS, under some circumstances. This commitment was made in response to problems outlined for these groups within the areas of health and social care including housing, education of children with parents in the military and within health looking at provision of mental health care for veterans. With the increased intensity of conflict in the Middle East in 2007, the obligations of the government to members of the armed forces were brought to the fore of policy. In 2008 better healthcare for veterans was highlighted in the new Military Covenant, specifically how veterans' health differs from the general population and pledging to raise awareness among healthcare professionals about the needs of veterans so that they could be better met by the MOD (Ministry of Defence 2008). This was in keeping with the guidance disseminated by the department of health at the end of 2007 stating that priority treatment of veterans was to be extended effective from the 1st of January 2008 (Department of Health 2007). Previous guidance stated that those veterans who had been granted a war pension or received compensation for conflict related health problems would receive priority treatment if they presented with further problems associated with the complaint for which they received compensation (Department of Health 1997). The extension of this guidance from the 1st of January 2008 meant that all veterans, as defined above were then entitled to priority treatment within the NHS for a complaint associated with their time in service (Department of Health 2007). This extended access meant:

"GPs are therefore asked, when referring a patient that they know to be a veteran to secondary care for a condition that in their clinical opinion may be related to their military service, to make this clear in the referral (as long as the patient wishes the referral to mention they are a veteran)."

Where secondary care clinicians agree that a veteran's condition is likely to be service-related, they are asked to prioritise veterans over other patients with the same level of clinical need. But veterans should not be given priority over other patients with more urgent clinical needs."

(Department of Health 2007, p3)

3.3.3.2 *Prosthetic provision for veterans*

The 2008 Military Covenant was updated in the form of a Government command paper which made specific reference to the provision of prostheses to veterans (Ministry of Defence 2008). Command papers are Government papers which are presented to Parliament in the UK and are usually published in a numbered series. This command paper stated that the prostheses that were provided with by the MOD would be matched by the NHS when they required replacement. This was emphasised by the Department of Health later that year when they published guidance for Strategic Health Authorities in England to indicate that they should be aware of the amputees that would be discharged from the services over the subsequent years with prostheses which may differ from those ordinarily prescribed by the NHS. They indicated that it was up to the individual primary care trusts (PCTs) to organise their prosthetic commissioning arrangements to accommodate this. This guidance to PCTs outlined that they should be replacing these limbs when required with *'appropriate replacements.....provided that they continue to meet their individual needs'* (Department of Health 2008). These pledges were echoed by the devolved Governments in Scotland and Wales (The Scottish Government 2008). In 2010 this information was reiterated firstly in a written ministerial statement by the Minister for Health in January 2010 followed by a Department of Health note to all prosthetic centre managers in England stating that where clinically appropriate those veterans with a prosthesis should have this replaced to a standard equivalent to that provided by the Defence Medical Service (DMS). The written statement also extended this assurance to all those veterans from all past conflicts, where a change or increase in prescription was clinically appropriate (Department of Health 2010b; O'Brien 2010). It was pledges like these that did not have financial backing or planning which raised concerns in the NHS about how they would be met.

In 2011 the first tri-service covenant was published by the Ministry of Defence qualifying this provision slightly (Ministry of Defence 2011). In this document the pledge was reiterated that those who required prostheses as a result of injury during service after discharge from the military should be provided with limbs to the standard of that provided by the DMS, this time subject to need. This meant that in cases where it was no longer deemed appropriate then the prostheses would not need to be replaced like for like with those provided by the DMS. This publication also highlighted the work being carried out by Dr Murrison on current prosthetic provision for veterans in the UK, indicating that recommendations made in this report would be looked upon favourably by the UK Government.

3.3.3.3 *The Murrison Report*

Despite all of the pledges made by the UK Government up to and including 2010 concerns remained. These concerns were about the ability of the NHS to cope financially and with respect to the expertise required to treat these complex amputee veterans with state of the art prosthetic components. Dr Murrison was commissioned by the Government in early 2011 to review veterans' prosthetic services in the UK, his findings were published later that year (Murrison 2011). His report reviewed current prosthetics services available in the UK to veterans with conflict related amputations. From the findings twelve recommendations were made, aimed at improving prosthetic services for veterans in particular. These recommendations can be found in full in Table 5. All of the twelve recommendations outlined were accepted by UK Government (Murrison 2011).

Table 5: Recommendations of the Murrison Report (Murrison 2011)

1	Ministers should take appropriate powers to provide for national commissioning for specialist prosthetic and rehabilitation services for amputee veterans through a small number of multi-disciplinary centres in England, adequately resources and determined through a tendering exercise.
2	Equivalent and complementary provision should be agreed with the devolved administrations.
3	Veterans should be able to access mainstream NHS provision through a DSC of their choice.
4	Each specialist centre should have provision for a BLESMA support officer.
5	The trial of the MOD Seriously Injured Leavers' Protocol and the MOD/NHS Transition Protocol have potential to improve handover from Headley Court and Personnel Recovery Units to DSCs and should be expedited with attention given to a refined system of case management including a comprehensive statement of needs and prescription on transition to the NHS.
6	The National Institute for Health and Clinical Excellence (NICE) should be tasked with the production of national guidelines for prosthetic prescription and rehabilitation for all amputees including provision for military amputees.
7	A prospective study of amputee veterans' long term outcomes should be commissioned.
8	The review supports the relocation of the Defence Medical Rehabilitation Centre from Headley Court to form part of the Defence and National Rehabilitation Centre. Closer integrated with the NHS holds considerable potential for service attributable amputees at all stages of the patient pathway as well as the wider civilian amputee community.
9	There should be a programme of military/civilian exchange and capacity building for healthcare professionals to grow the specialist prosthetic and rehabilitation network rapidly.
10	The NHS Healthcare Travel Cost Scheme currently available to War Pensioners to be extended to beneficiaries of the Armed Forces Compensation Scheme for the purpose of attending DSCs and accessing associated healthcare.

11	Case management to ensure that, as far as is reasonable practicable, amputee veterans abroad are able to access an equivalent standard of prosthetics and rehabilitation as they would have enjoyed had they remained in the UK.
12	An audit of the new funding arrangements should be undertaken after five years

3.3.4 Conclusion

The understanding of the need for improved provision for veterans in a number of areas including health and social care has grown, particularly from the beginning of the 21st century. This need for improvement has been translated into a series of policies driven by the MOD and UK Government to be adopted and implemented in England and by the devolved administrations. Part of this improved provision has included increased priority of access for veterans within the NHS since 2008 and an increase in the level of prosthetic provision, over and above what is provided by the NHS to civilians, for veteran amputees. This has evolved during a period of time where there have been increasing numbers of veteran amputees coming into the NHS from recent conflicts, particularly in Afghanistan. In response to this the Government commissioned the Murrison report and accepted all twelve recommendations which it made. The Government then went on to support these recommendations by announcing that it was investing £15 million to meet the recommendations made (Marsden and Lancefield 2011). The main impact of the Murrison report for prosthetic NHS services in England were that nine specialist veteran centres were appointed through a blinded tendering process. These specialist centres are not new stand-alone services, rather they are an additional function of nine existing DCSs in England. In addition a panel was created so that applications could be made for additional funding for amputee veterans within the NHS requiring extra funding for their prosthetic treatment. Applications to this fund are made by the patients' prosthetist or DSC.

3.4 Interviews with key informants

3.4.1 Aim

The aim of the meetings and interviews which comprised the third stage of the scoping study was to explore if decision making related to prosthetic care was an important area of research for prosthetic services in the MOD and NHS. During the policy document review I had created a basic pathway of care within the MOD (see Figure 6), these meetings and interviews were used to refine and build on this pathway to identify the key decision making points in the rehabilitation process in the MOD. Finally, these interviews were used to begin to identify the factors which influence prosthetic prescription choices in both settings and to identify any barriers and facilitators to carrying out research in this area.

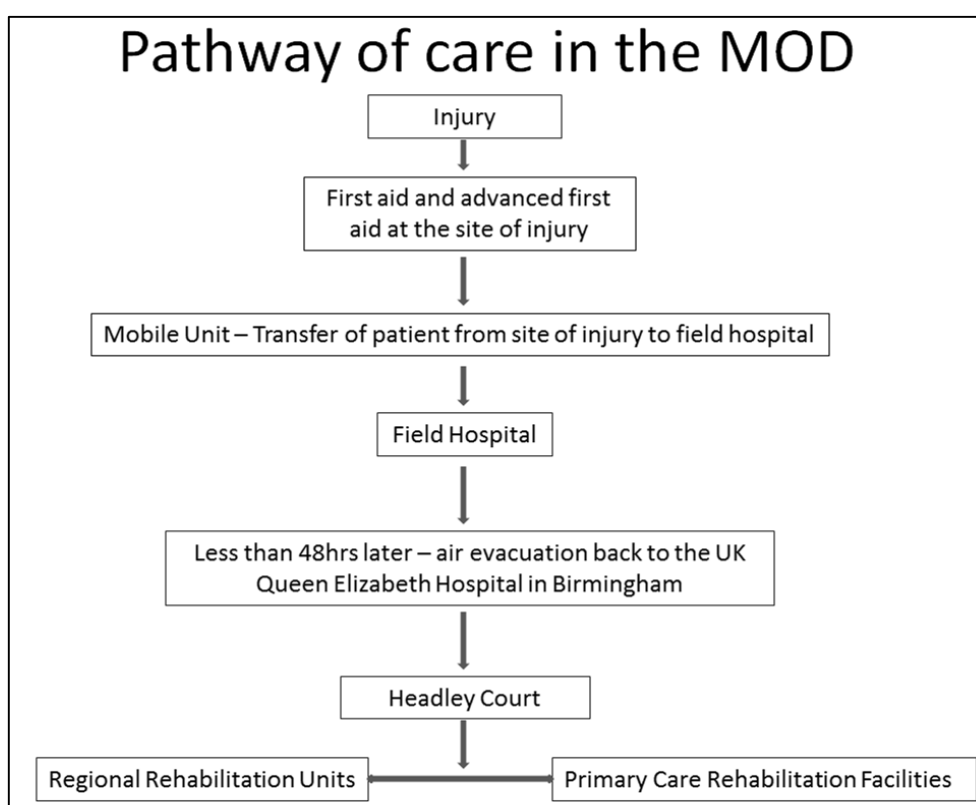


Figure 6: Basic pathway of care in the MOD

3.4.2 Method

Meetings and interviews were carried out with a number of key stakeholders within the NHS, MOD and charitable sectors. The strategy which I used to identify key informants was snowball sampling. In this method of sampling a small number of initial subjects are identified by the researcher and it is those initial subjects who identify further subjects in the population of interest (Gray 2009a). The first informant identified was a member of the Territorial Army known by the supervisory team. They were able to provide insight into the military side of the process and provide a brief outline of the pathway of care for amputees in the military. In

addition they were able to provide several further contacts. This technique was used with each subsequent stakeholder. Over the next five months a series of meetings and interviews were carried out with a total of eleven stakeholders including prosthetists, physiotherapists, and rehabilitation consultants, a veteran from the MOD and NHS as well as other service personnel.

Most of these meetings and interviews were recorded and transcribed verbatim. As this scoping study was purely exploratory and was being used to develop the main study no ethics approval was sought. The stakeholders verbally agreed to the meeting being recorded if they were willing for this, if they preferred that a recording not be taken then field notes were made during the course of the meeting. Recordings were helpful due to the rich information that each of the key stakeholders provided, they also meant that the information which was gathered could be used to the fullest extent.

These interviews were able to fulfil two purposes. In the first instance the basic pathway of care in the MOD developed during the policy document review (Figure 6) was used in the initial interviews to prompt discussion about the organisation of care in the military setting for amputees. During the course of these discussions the basic pathway was developed further through an iterative process of refining the pathway after each interview. At the end of this process the pathway of healthcare for seriously injured military personnel was clearly defined (Figure 7). With the pathway of care becoming clearer it could be discussed in more depth with subsequent stakeholders to identify which stages in the process were the key decision making points and who was making these decisions. These discussions also covered topics such as the barriers and facilitators within the organisation of care in the military. In addition, meetings with NHS and user/charitable stakeholders gave the perspective of the interface between the MOD and the NHS as well as the importance of charitable input for personnel both before and after discharge from service.

3.4.3 Analysis

Due to the large volume of information which was collected during this process a systematic approach to analysing the data was taken. It was then possible to use these preliminary findings along with the findings from the other two elements of the scoping study to inform the direction of the main research project in the absence of a strong body of relevant research literature. Framework analysis was used. Framework was developed by researchers from the National Centre for Social Research (NCSR) based in the UK in response to the need for the analysis of qualitative research to be more systematic and transparent (Bryman and Burgess 2002). This method aims to make findings more robust as the documentation of the analytical

process and the interpretations derived from that process allows others to judge the findings. It is a matrix based analysis method which is both deductive and inductive (Bryman and Burgess 2002). The deductive aspect allows for specific questions posed by the researcher to be answered while the more inductive aspect brings further findings from the data that were not the primary focus of the research but which can enrich the project findings as a whole.

3.4.4 Findings

The findings from these meetings and interviews are discussed within six main themes.

1. Ministry of defence organisation of care
2. NHS organisation of care
3. Decision making – prosthetics
4. Decision making – discharge
5. Process of transition of care
6. Communication between the NHS and the MOD
7. Patient population, demographics, size of the problem

Four of these themes had been defined before analysis (a priori themes) based on the aims of the meetings and interviews outlined previously, these included; MOD organisation of care; NHS organisations of care; Process of transition of care and; Communication between the NHS and the MOD. The themes which emerged from the data were; Decision making - prosthetics; Decision making – discharge and; Patient population, demographics and size of the problem.

3.4.4.1 Ministry of Defence organisation of care

The key point that arose under this theme was the physical pathway of the care within the MOD which was discussed in detail by the majority of key stakeholders within the military. As the interviews progressed an important distinction appeared, the refined pathway of care (Figure 7) could be split into two distinct sections. The first of which was the administrative pathway of care (Figure 8), this section of the pathway coordinates how personnel are managed when they are sick or injured and is a vital part of provision of care within organisations as large as the MOD. The second is the rehabilitation pathway of care (Figure 9) which outlines the process of care for injured personnel from the point of injury to the time when they are able to return to service within their unit or they transition back to civilian life.

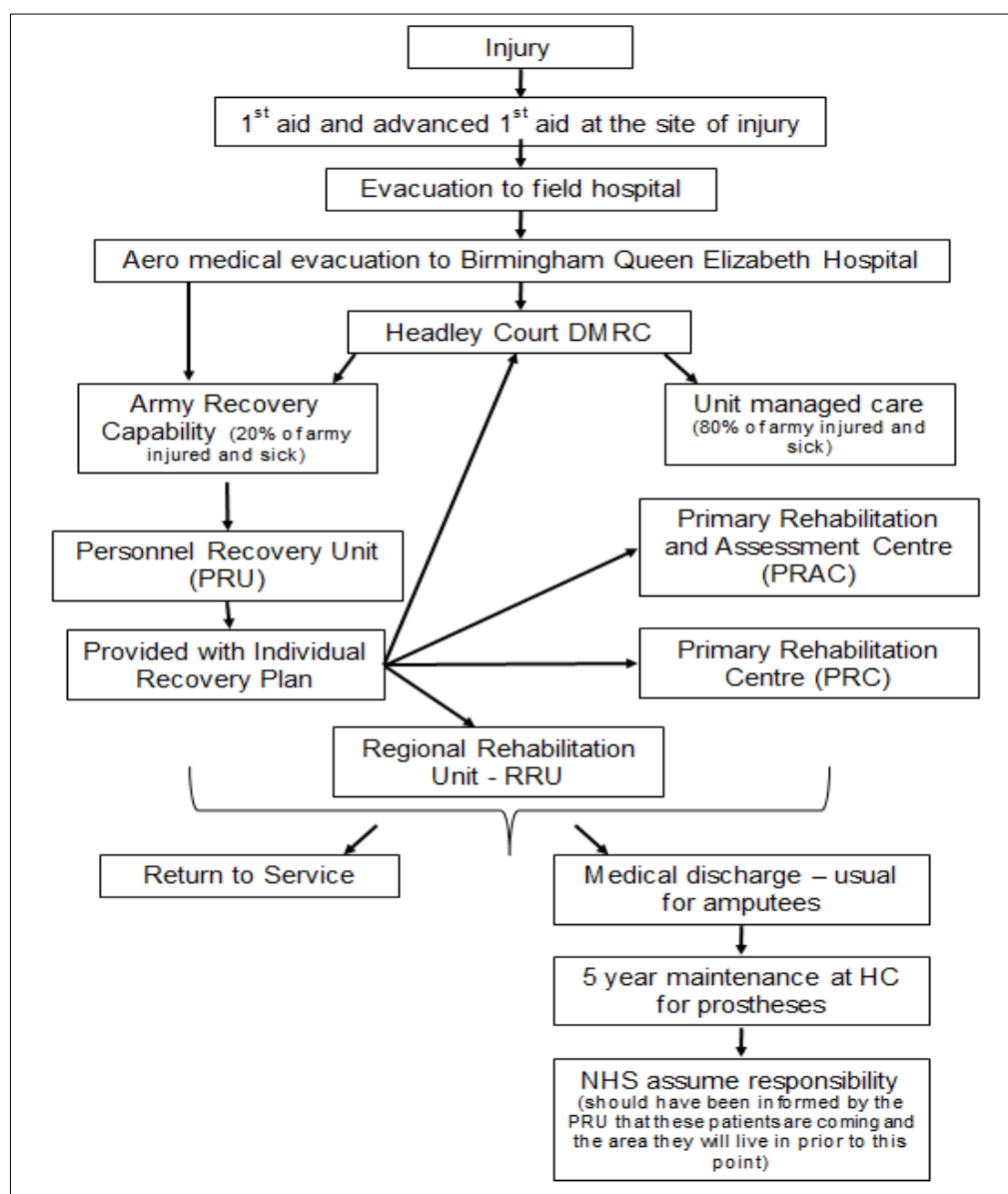


Figure 7: Refined pathway of care in the MOD

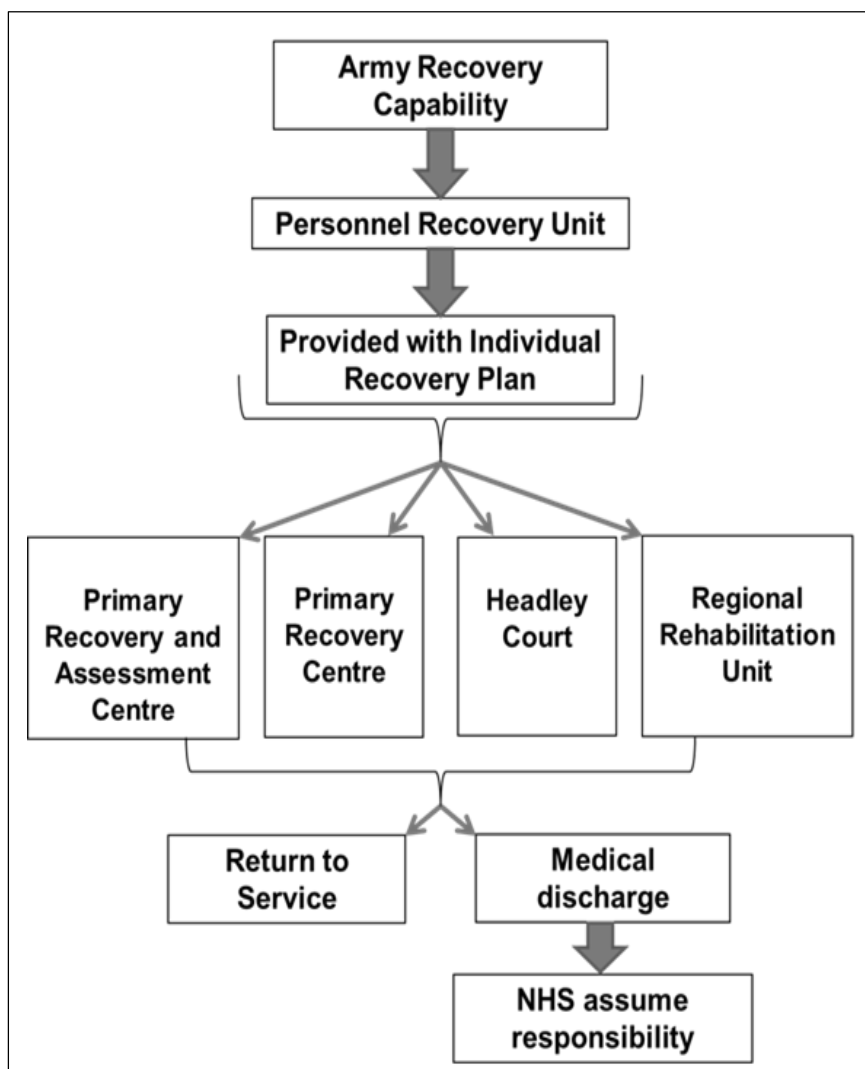


Figure 8: Administrative pathway of care

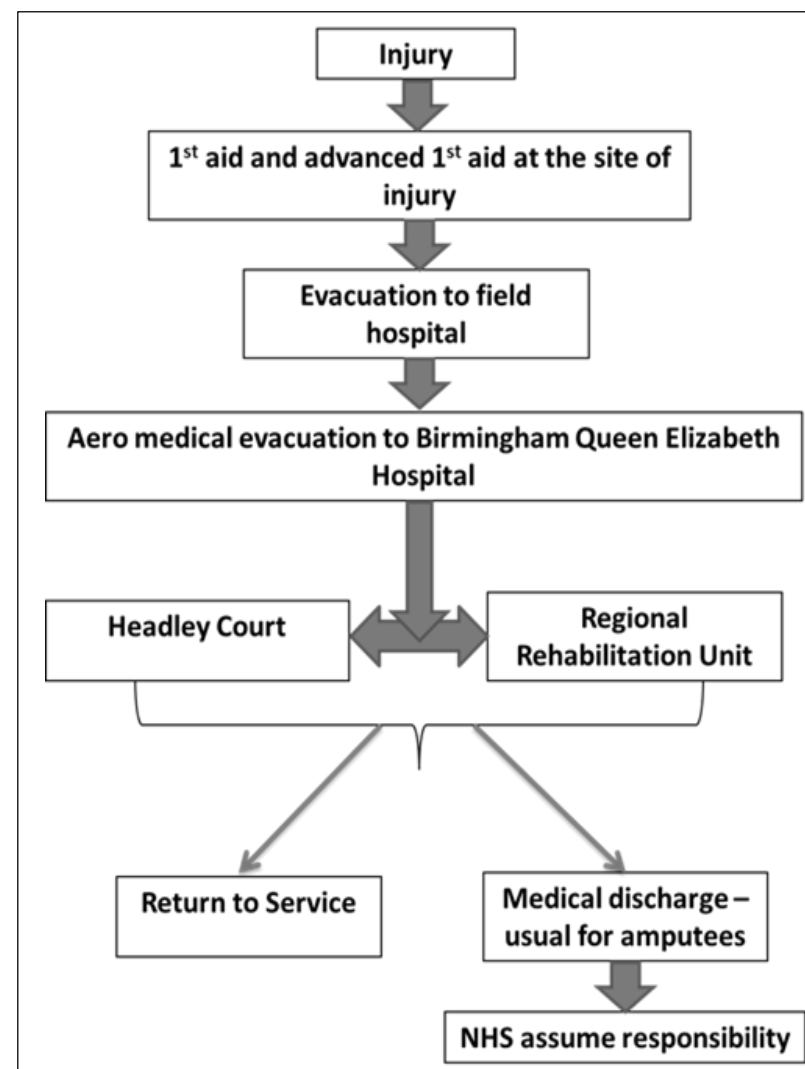


Figure 9: Rehabilitation pathway of care

The high standard of care delivered by the MOD to their sick and injured was highlighted by both military and NHS stakeholders with special mention made of the standard of 'state of the art' prostheses that military personnel were receiving. Conversely, it was mentioned by more than one stakeholder that despite the high level of prosthetic care they were receiving, the organisation of care could sometimes be a hindrance. For example, the system of centralised prosthetic care delivery at the DMRC meant that in all cases an amputee had to travel from wherever they were in the UK to Headley Court in order to have any prosthetic review, related care or repairs carried out. Additionally, it became apparent that even if soldiers could have been seen in Scotland for larger repairs or maintenance prior to discharge from the Armed Forces, there was little expertise available in the types of prostheses military amputees were being prescribed to allow this to happen (mid 2011).

3.4.4.2 NHS organisation of care

This theme reflected the points raised by those in the military relating to their feelings that there was a lack of expertise in the NHS to maintain and prescribe types of prostheses that were being prescribed by the MOD. NHS prosthetic centres in Scotland had been working over a number of years to produce protocols for these military patients, however, it was clear that these were not yet complete or sufficiently robust for NHS services to understand how they would cope with the anticipated increase in military amputee numbers.

Some apprehension was also apparent from the NHS regarding their ability to provide the level of prostheses, on a financial level, to these military amputees when they became veterans and were under the care of the NHS. Of particular concern was the number of limbs that military personnel were receiving. For example, it was reported that one recently discharged military patient had been provided with eight limbs by the DMS.

From the military perspective it was admitted that how these veterans would be cared for in practice under the NHS was not yet known. At that point the number of discharged military personnel from recent conflicts with SOTA components was small. While the anticipated numbers were still relatively small, it was felt that the burden on the NHS could be considerable due to the high specification and number of limbs that these military personnel had been provided with by the MOD.

Further aspects of the organisation of prosthetic care within the NHS were considered problematic, including the variety of models of prosthetic delivery within the UK's NHS (see

2.4). It was reported that there varied models of prosthetic care delivery could create some disparity in the organisation and delivery of this care to veterans across the UK.

3.4.4.3 Decision making – prescription

The point above also relates to the finding of this theme. Stakeholders reported that variations in the organisation of care between centres could lead to differences in the way that clinicians were making prosthetic prescription choices. It was felt that this could therefore affect the prosthetic prescription choices being made and also how these decisions were made. This variation from service to service was also noted to affect prosthetic prescription for a number of other reasons. These included the contracted model of care which was felt could be associated with prescription biases. Further combined with restrictions imposed in the NHS on which prosthetic components which they were unable. Information gathered with regards to this point were mainly Scotland based perspectives.

Under this theme it was highlighted how complex the prosthetic prescription process was with many factors raised which influenced the process. These included who was making the prescription choice, when that decision was made, influencing factors such as patient choice, cost and changing prescriptions. Participants from both the MOD and NHS felt differently on several points, for example, the cost of the prosthesis was very much at the forefront of the mind of the NHS prosthetist whereas MOD consultants believed that money was not and should not be a restraining factor when prescribing prosthetic limbs in the DMS. These differences were also evident in relation to prescribing. The NHS prosthetist felt that patients should demonstrate their commitment to achieving a higher level of activity before they would prescribe components that would inevitably cost more. MOD stakeholders indicated that in the case of military amputees they were generally able fit young men and as a result should be provided with the limb or limbs required to get back to that level.

Both the MOD and the NHS stakeholders indicated that involving the patient in prescription was important, but that more information from prosthetists in the MOD would be important in exploring this concept more fully.

3.4.4.4 Decision making – discharge

The other main area of decision making which was identified within the pathway of care was the point at which it is decided whether a member of military personnel should remain in service after having undergone amputation or if they should transition back to civilian life.

Much was made of the process which occurred to make the correct decision for the amputee and the military. Stakeholders emphasised that the system of movement out of the army had changed somewhat. The process of medical discharge was very much about throughput and maintaining the operational capability of the military within continued operational strains. However, as much as possible they considered the wishes of a member of personnel about when they were discharged. Emphasis was also placed on 'looking after their own' and the inherent knowledge that they had an obligation as far as they could to look after their injured for as long as possible and to get them to a position where they were as well rehabilitated as they could be before being discharged, even if this was a considerable time after injury. MOD stakeholders noted that having an input with veterans after discharge could be difficult and that in the past it has been a case of the veteran leaving the military to an unknown civilian life beyond. From that point there was little that the military could do to assist.

“...so when we arrive at the gate, and wee Johnny’s pushed through, the people that he needs to deal with, he’s already been dealing with, because my remit stops at the boundary fence.”

(MOD stakeholder)

3.4.4.5 Process of transition of care

This theme was raised by almost of all of the stakeholders with the focus mainly on the complexities associated with the transition of care and the remaining unknowns with respect to amputees from conflicts in Iraq and Afghanistan. The immaturity of the system of transition of care for this group was also highlighted as an issue in a number of cases. As was also seen from the policy review there are documents and agreements which dictate, to a degree, how the transition from military to civilian life should be managed and this was very much reflected by informants raising these underlying policies during discussion. The key areas that were raised under this theme were the employability and training for those being discharged from service, the organisation and scope of the available training, how this can facilitate the transition but also the points at which the organisation itself could also hinder the process of transition. Additionally, it became clear from a number of stakeholders that they identified communication between of the MOD and external organisations as important, from local councils to charities, these connections could have a great influence on the smooth transition of military personnel back to civilian life. Finally, some of the

difficulties that were identified as being likely to arise in the transition from the MOD to the NHS were managing the expectations of ex-servicemen between what they actually require prosthetically in comparison to what was provided by the MOD and changes that could be made to their prescriptions as a result.

3.4.4.6 Patient population, demographics, size of the problem

This theme highlighted that while the actual patient population affected by these issues of changes in prosthetic care were small; they are such a complex group that their needs are great and will require significant resources to care for them in the long term in the NHS. Stakeholders also highlighted the unique nature of this population in particular that they are in general an active dynamic group.

3.5 Scoping Study Discussion

The scoping study found that Government pledges had been made regarding the ongoing prosthetic care for veteran amputees who had been provided with 'state of the art' prostheses during their time under the care of the DMC. However, it was not transparent how this was going to be achieved and how the £15 million pledged by the Government in 2011 would cover all of the recommendations made in the Murrison report. This was part of much wider issues relating to care of veterans in general and those with injuries and other healthcare issues transitioning from the services back to civilian life. It could be seen from the evolving policy context that as time has moved on from 2008, the offer of equivalent prostheses to those provided by the DMs became more qualified, with the more recent documents stating that veterans limbs would be replaced and maintained by the NHS 'as appropriate'. The Murrison report highlighted the importance of understanding the experiences of service related amputees as they transition to civilian health care. The recommendations in the Murrison report created the potential for inequality between MOD and NHS care (Murrison 2011).

The recommendation that the National Institute for Health and Clinical Excellence (NICE) be commissioned to produce national guidelines for prosthetic prescription and rehabilitation for all amputees was premature. The lack of guidelines in the prosthetics profession requires to be addressed but commissioning them is not straightforward. There is currently a lack of primary research on efficacy of different prosthetic treatments, reviews of implementation of care, or studies of patient experience to inform guideline production.

Current research in this area has focussed on the technical aspects of different prosthetic components with a large amount of this research being funded by the companies who manufacture those components. Sparse research has been carried out into the way that prosthetists make prescription decisions and what impacts on that decision making process, without this knowledge it would be difficult to bring any standard evidence informed guidance to prosthetic care provided in the UK. As discussed in the literature review most of the research regarding prosthetic care in the UK has focussed on older amputees rather than trauma amputees.

3.6 Context

The scoping study highlighted widespread concerns about a possible surge in the numbers of amputee veterans coming into the NHS and its possible impact on NHS prosthetic services. Additionally, concerns had been raised by the Armed Forces and third sector parties about the level of care that discharged military amputees would be able to receive from the NHS. In response the Government commissioned the Murrison report whose twelve recommendations related to the structure of prosthetic care delivery for veterans as well as further research required. These recommendations only related to services in England but urged the devolved administrations to meet these recommendations locally. This meant that while the recommendations of the review were clear in England, this was not the case in Scotland as a result NHS services in Scotland were left uncertain as to how prosthetic services for veterans should and would be provided in the future. Question one of my thesis was developed to explore this situation.

1. What are the issues and drivers for prosthetic service delivery for trauma amputees, in particular, current and anticipated service related amputees?

However, during the course of the project it became clear that the anticipated surge in amputee veteran numbers in Scotland had not yet occurred, although there had been amputee veterans discharged during this time. Therefore the data which was collected from prosthetists in relation to this question was not fully able to answer the research question. This data was therefore extracted from the main analysis and used to provide information about the context of prosthetic service delivery in Scotland during the time of this research project. It also provides the context about the changes which were implemented as a result of the Murrison report in Scotland. The data which contributed to this context was gathered from service managers, lead prosthetists and prosthetists. One of the most significant

changes which was made related to the funding for amputee veterans within the NHS in Scotland. These financial aspects are discussed with respect to context here and are also incorporated into the data analysis in the following chapter on their impact on prosthetic prescription.

3.6.1 Veteran amputee care structure in the NHS

Initial interviews showed that in April 2013, a year and a half after the publication of the Murrison report there remained no clarity on how funding for future amputee veterans would be provided in Scotland. Additionally it was unclear where the budgetary responsibility for amputee veterans lay, for example, would the care for these patients be managed from each prosthetic centres existing budget or would there be a tendering process which would provide additional funding for successful centres as had been the case in England. The next service manager was interviewed seven months later, at that stage it was becoming clearer how the needs of this group of amputees would be met. This interview followed an announcement from the Scottish Government that they would provide funding to meet the recommendations that the Murrison Report had made for England within Scottish prosthetic services. As well as this, two of the existing limb fitting centres in Scotland had been appointed to act as specialist veteran centres. They reported that once this decision had been made there were further negotiations about the funding and remit of this specialist service. The result of these negotiations between the specialist centres and the Scottish Government was that funding provided by them for these services could cover associated increases in staff costs as well as components for veterans and importantly that the funding could be used to fund prosthetic components for both amputee veteran and civilian amputees. Despite these changes there was still uncertainty around the numbers of new amputee veterans that this newly formed service would be responsible for over time. In addition, they did not know how many existing amputee veterans already within their service would be eligible to apply for this new funding and finally how many of their existing civilian amputees would be eligible to apply and how that process would be managed. It was seen as important to service managers and prosthetists that they provide an equal service for civilian and veteran amputees where possible.

3.6.2 Prescription criteria

It was important to service managers that they were able to be as transparent as possible about the process of allocating this new funding. In order to achieve this both specialist centres were working together to create a joint panel to which both civilian and veteran

amputees could apply for additional funding for SOTA components. Prior to the creation of this panel prosthetic services across Scotland had outlined a set of components (SOTA components) that would not be prescribed through the NHS. The additional funding provided them with the opportunity to start prescribing these types of components to eligible patients. As part of this process service managers and prosthetists were looking to develop prescription criteria for these types of components, again to help with the transparency around when these components could be provided. It was also reported that they had requested information from the MOD around the prescription criteria that they were using for the components that they were prescribing at that time but that this information had not been made available to them.

3.6.3 Clinician and patient expectations

The anticipated surge of amputee veterans produced a variety of opinions relating to both clinician and patient expectations of NHS prosthetic care. When discussing patients' expectations it was a commonly held view among service managers and prosthetists that they felt that they had very high expectations. These expectations came from anecdotes around the care these patients' received at Headley Court as well as some first-hand experience of the types of components that they had been provided with there. It was the understanding of a number of the participants that military amputees who had not yet been discharged had fears about the level of care that they would receive from the NHS after discharge. The service manager who was interviewed early on in the process had felt that under the funding structure which existed then, these patients would be disappointed with the care that the NHS could provide considering reports that they had heard about prosthetic provision at Headley Court. It was felt that that these expectations could prove difficult to manage. This was in part attributed to the publicity that this group were receiving and that this could have a disproportionate effect if any complaints of NHS services were made by amputee veterans post discharge.

Conversely, some of the prosthetists interviewed had had experience of treating recent amputee veterans. They reported that these patients had indicated that they were pleasantly surprised by the care they had received from the NHS, additionally they had heard accounts from patients around negative experiences of their care at Headley Court. Prosthetists found that members of this group had realised that there were some things that would be different in the NHS, such as delivery times for limbs, but that they accepted this and didn't perceive it as bad care.

Service managers and prosthetists had their own expectations of what the addition of this group of patients would mean. For some it was perceived as an exciting challenge and an opportunity to expand their knowledge in new and complex cases. Some perceived it more negatively with fears around working with this new and complex group. Overall there was a feeling that that their experience as a prosthetist to date made them feel capable of meeting these new challenges head on and that they would provide a learning experience. In order to meet these challenges additional training was being undertaken in different SOTA components they had no previous experience of using. They felt this was an important process to go through so that they could provide a high quality service to this new group.

3.6.4 Parity of Care

With recommendations from policy indicating that military patients should have their standard of care and components maintained by the NHS concerns were identified around the parity of care between veteran and civilian patients. Some of the participants in this study indicated that this was one of their biggest concerns in this landscape of change in prosthetic service delivery. The personal opinions of some of participants indicated that they did not feel that having been in the military should necessarily entitle them to receive a different level of care from the civilian population and that this was a difficult approach to take and left them open to criticism. This was not to say that military veteran patients should be disadvantaged but that to offer them a different level of service was difficult as it forced the issue around who was more or most deserving of a certain level of care.

Others agreed about their deserving of a high level of care for their sacrifice for their country but felt that they were duty bound to provide that care to all of their patients. Some found this was an issue which went against the very premise of the care that the NHS was designed to provide, equal service at the point of care. It was felt that the decision had been made at a government level for an enhanced service for military amputees and that at that level a two tier system of prosthetic care had been accepted. It was felt by some that introducing a two tier system could create difficulties between the service and civilian patients who could question the disparity in the care that they were receiving compared to that received by amputee veterans.

Connected to the issue of parity of care was the common feeling that if there were patients with different levels of componentry who may be treated in the same room that this could evoke comparisons of care. Some prosthetists acknowledged that this was already evident

among NHS patients. In cases where the differences in components could be clinically justified, as they were currently among NHS civilian patients, they were able to manage those situations using their own clinical reasoning and expertise. However, they felt that if these situations were financially driven, as was expected to be the case between civilian and veteran patients, they felt that this would be more difficult to cope with and that a difference in level of care between veteran and civilian groups of patients could become apparent.

It was reported that it was equity of care which had been the driving force behind the decision not to provide some of the SOTA components across Scottish centres. Each prosthetist was able to identify patients in their case load that would have benefited from one or other of these types of components; they further understood that on a one off basis they would financially be able to achieve this. Despite this they realised that financial restrictions would mean that they would not be able to provide them for everyone under their care who would potentially benefit from them. They also discussed that there was insufficient evidence the cost benefits of these types of components. The combination of these factors prevented prosthetists from being able to justify the prescription of these products at that time.

The issue of parity of care was of concern to both prosthetists and service managers at the beginning of this study. However, the changes made to the funding for amputee veterans during the time of this project began to allay these fears. The additional funding which was to be provided combined with the fact that it could be accessed on a case by case basis for both civilian and military amputees indicated that there should not be disparity among similarly eligible patients.

3.6.5 Transition from the MOD to the NHS

The management of the transition of care for these patients was discussed throughout the data collection process but was, like funding, seen to evolve over that period. Initially the process of transition of military patients from the MOD into the NHS was handled badly and without a recognised system. Reports were given of various ways that amputee veterans had joined the NHS. Over time it seemed that a more robust process was being put in place to make the transition process smoother. This involved a 'hard facts meeting' prior to discharge from the Armed Forces. Prosthetists were invited as well as representatives from other external organisations to meet with the member of military personnel who was to be discharged. From the prosthetists' perspective this meant firstly that they were aware an

amputee veteran would be joining their service and have an idea of the timescale of that happening as well as providing an opportunity see the prescription that the patients had. It also gave them a chance to invite them to come and visit the centre they would be attending after discharge. Hard facts meetings were discussed by both service managers and prosthetists, they were felt to be helpful both from the perspective of preparation of prosthetic services for new amputee veterans as well as giving them the opportunity to address any fears that the patient might have had about the care that they could expect to receive after discharge. This links with the expectations discussed above and the importance of having a structured transition process.

One prosthetist talked more in depth about their centre having good contact with their local personnel recovery unit (PRU), which was helpful to them in the process of transition. They were shown a list of the men that were attending the PRU, likely to be discharged in the near future and likely to be in their service catchment area. Some prosthetists indicated that there seemed to be lack of communication between Headley Court and the PRUs. This lack of communication was thought to mean that Headley Court did not necessarily know when a patient had been discharged from service resulting in issues around the transfer of individual patient notes from MOD to the NHS.

The organisational process for patients moving from the MOD to the NHS appears to have improved and is continuing to improve over time. The issue that remains are the transfer of patient notes and information between the two organisations which can result in gaps in the NHS clinicians understanding of the prosthetic care which the patient has previously received.

Conclusion

With the publication of the Murrison report in 2011 and the subsequent acceptance of each of its recommendations by the UK Government shortly after heralded a period of uncertainty for prosthetic services in Scotland. The recommendations made focussed on changes in the delivery of care and funding for veteran amputees receiving prosthetic care in England. However, service providers in Scotland had provided evidence for the review and there was a strong feeling that similar recommendations would be made in Scotland over time. Evidence of this uncertainty could be seen in the interviews which were carried out at the beginning of the data collection period. This uncertainty was related to several aspects; a lack of knowledge of the numbers of amputee veterans that would be requiring prosthetic

care in Scotland in future years, no knowledge of the funding structure for dealing with this group and importantly no clear indication from the MOD what their prescription criteria for providing SOTA components were. Over the period of data collection it became clear that some of these uncertainties were being replaced by new processes and plans, perhaps most importantly the financial assistance that had been agreed with the Scottish Government in order to meet the recommendations for this group of patients in Scotland. In addition, service managers from the two newly appointed Scottish veteran prosthetic centres had managed to negotiate that this money could provide extra staffing as well as additional funding for the civilian population. It was felt that this went some way in dealing with the other concern raised around parity of care between civilian and veteran amputee patients. Finally, it could be seen that progress had been made in the process of transition of care for veteran patients leaving the MOD and that this was a system that was working well from the perspective of prosthetic service providers.

This chapter has given an account of the process which was undertaken to help in the development of the research questions and how they evolved during this research project. The following chapter sets out the methods which were subsequently employed to explore prosthetic decision making and provision for trauma amputees in the UK.

4 Chapter 4 – Methodology, Research Design and Methods

This chapter describes the methodology underpinning the design and methods used in this research project. It begins by giving the original aims and research questions refined on the basis of the three elements of the scoping study. Some difficulties were encountered in relation to ethics and permission for access to MOD personnel resulting in changes to these aims and research questions. These problems and changes are briefly outlined at the beginning of the chapter. The remainder of the chapter gives an account of the amended research aims, research questions and methods used in the completion of this research project.

4.1 Original research aims and research questions

The original aims of the project were to compare the prosthetic decision making processes of clinicians working in the MOD with those working in the NHS in Scotland and to identify if there were any problems which were unique to this process for those serving in the military compared to civilian trauma amputees. The original aims also included exploring patients' experiences of prosthetic care in the MOD and NHS setting as well as to explore the process of transition for those military amputees who had moved from the MOD to the NHS for their prosthetic care provision. To address these aims the following research questions were posed:

1. What factors (clinical and non-clinical) influence clinical decision making in prosthetic care for civilian amputees and service attributable amputees within the NHS and the MOD?
2. What problems are unique to the decision making process in prosthetics for those serving in the military compared to civilian amputees?
3. What are trauma patients' experiences of prosthetic care in the UK?
4. What are the experiences of involvement in decision making of civilian trauma amputees and service attributable amputees?
5. What are the experiences of transition of prosthetic care for those amputees moving from the MOD to the NHS

These were the research questions which formed the original basis for my doctoral research project. In order to address these questions I required access to clinicians working in prosthetic rehabilitation at Headley Court and amputee patients receiving prosthetic rehabilitation there. The full protocol for this project plan can be found in Appendix 1. I sought access to these MOD based staff and patient groups as well as the identified NHS based groups. After a complicated and lengthy application process access to the MOD based groups was refused, as a consequence a number of changes required to be made to the project. A table outlining the changes and the reasons for these can be found in Appendix 2. The remainder of this chapter will discuss the amended project.

4.2 Aim

The overarching aims of the amended project were firstly to explore prosthetists' decision making in prosthetic prescription in trauma amputees. Secondly, to explore trauma patients' experiences of prosthetic care and their involvement in their care. Finally, to explore the transition of prosthetic care for amputees moving from the military setting to the NHS after discharge from the Armed Forces. These aims were addressed by the following research questions:

1. What are the issues and drivers for prosthetic service delivery for trauma amputees, in particular, current and anticipated service related amputees?
2. What factors (clinical and non-clinical) are used in the judgements and decision making of prosthetists during prosthetic prescription for civilian trauma amputees and service attributable amputees?
3. What are trauma patients' experiences of prosthetic care in the UK?
4. What are the experiences of involvement in decision making in the NHS and the MOD of traumatic civilian and service attributable amputees?
5. What are the experiences of transition of prosthetic care for those amputees moving from the MOD to the NHS?

4.3 Methodology

This section provides a brief description of various methodological approaches. The exploration of these approaches highlight which are the most appropriate to answer the above research questions.

There are two paradigms which view knowledge and the production of knowledge in two distinctly different ways: positivism and interpretivism. Positivism within the social sciences draws heavily on the research methods of the natural sciences, where it is considered that all of the aspects of the world around us can be observed and measured and 'are as they are'. In this paradigm positivists consider that there is a single objective reality which can be tested using scientific methods. Within social sciences this is interpreted as all human behaviour resulting from external stimuli which can in turn be measured using objective scientific methods (Bowling 2009a). At its core, positivism argues that the social world exists externally to the researcher and that its properties can be measured through observation (Gray 2013). Positivists believe that real knowledge is produced through scientific testing and uses quantitative methods to achieve this.

Conversely, qualitative research methods are usually based on an interpretivist paradigm (Parahoo 2014). In this paradigm it is believed that the social world is subjective and that the researcher is part of that social world and can therefore have an influence on it (Giacomini 2013). Unlike the objective reality that is associated with positivism, the interpretivist paradigm proposes that there are multiple realities which are constructed by individuals and influenced by social interaction (Gray 2009a). This viewpoint follows a constructionist ontological position. The interpretivist paradigm theorises that there are multiple realities which exist and each person experiences their reality differently depending on their social situation (Holliday 2007).

As can be seen, positivism and interpretivism are two epistemological paradigms which view the construction of knowledge in different ways. Resulting from these different constructions of knowledge are the ways in which researchers, who espouse these paradigms, believe that knowledge can be procured. Positivism was the dominant paradigm in social science from the 1930's through to the 1960's when a number of challenges were raised (Gray 2009b). One of the main challengers was philosopher Karl Popper who suggested that a theory could not be proved merely through multiple observations because if that theory is refuted, even once, then it has been proven to be false (Popper (1968); cited by Gray (2009c). Sustained challenges to the positivist paradigm resulted in the introduction of a number of alternatives, with interpretivism being one of the most influential post-positivist paradigms (Gray 2013).

Table 6 shows the differences in terms of epistemology and methods between quantitative and qualitative research. These differences offer an explanation for the polarised use of different research methods arising from each epistemological view point. One of the main distinctions made between quantitative and qualitative research methods are their relationship to theory. In quantitative research, a theory or hypothesis is generally presented initially and tested during the research process in a deductive manner, while qualitative research is generally inductive and the hypothesis is generated throughout the research process. In this way the theory is the output of qualitative research whereas in quantitative research it tends to be the starting point.

Table 6: Some differences between quantitative and qualitative methods, adapted from Bryman (1999)

	Quantitative Methods	Qualitative Methods
Epistemological positions	Objectivist	Constructivist
Relationship between researcher and subject	Distant/ outsider	Close/ insider
Research focus	'Facts'	Meanings
Relationship between theory/ concepts and research	Deduction/ confirmation	Induction/ emergent
Scope of findings	Nomothetic	Ideographic
The nature of data	Data based on numbers	Data based on text

Until relatively recently researchers tended to adhere to either qualitative or quantitative methods of research, due to this split between the positivist and interpretivist ways of knowing. Johnson et al (2007) discussed how the blending of qualitative and quantitative methods was not new but it was not until much later that Campbell and Fiske (1959) first made it explicit how to use mixed research methods for the purpose of validation of findings through triangulation (using a number of methods or perspective to explore the same phenomena). There has been growing recognition of the place of mixed methods research as a third major research approach or paradigm (Johnson et al 2007). This third paradigm encompasses pragmatism; pragmatists believe that quantitative research methods are not necessarily only related to a positivist stance or that qualitative methods are always related to interpretivist stance (Gray 2009c). Pragmatism takes a step away from the epistemological stand point restricting the research methods used. Recently, more authors appear to be taking the more pragmatic approach recognising that the choice of research

methods should be based on the research questions posed rather than approaching a research problem from an epistemological stand point (Teddlie and Tashakkori 2003). Silverman (2013) argues that the approach used relates to the way in which the issue has been posed, and identifying the methods that are required to answer the research questions. Bryman (1984) talks about the inherently exploratory nature of qualitative research. As a trained clinician, and an early career researcher, I did not approach this project with a pre-conceived epistemological stand point. On considering the problem posed and the lack of existing research on the topic of prosthetists decision making and patient involvement, the developed research questions were exclusively exploratory and descriptive in nature. It seemed clear that the research methods which would best allow me to answer those research questions would be qualitative. As such I used only qualitative research methods in conducting this piece of work.

4.3.1 Qualitative research and the role of the researcher

‘Qualitative research begins with assumptions and the use of interpretive/theoretical frameworks that inform the study of research problems addressing the meaning individuals or groups ascribe to a social or human problem. To study this problem, qualitative researchers use an emerging qualitative approach to inquiry, the collection of data in a natural setting sensitive to the people and places under study, and data analysis that is both inductive and deductive and establishes patterns or themes. The final written report or presentation includes the voices of participants, the reflexivity of the researcher, a complex description and interpretation of the problem and its contribution to the literature or a call for change.’

(Creswell 2012a, p44)

This quote highlights the importance of the researcher within the qualitative role and places their reflexivity at the centre of the research process. Reflexivity is the process within qualitative research studies by which the researcher positions themselves within that piece of research. Researchers are required to be conscious of the biases, values and experience that they bring to the research and consider the way in which these could affect the research itself (Creswell 2012b). Making these aspects explicit in the reporting of qualitative studies is considered to improve the rigour of the research and is seen as a characteristic of a ‘good’

qualitative research study (Hammersley and Atkinson 1995; Holliday 2007). Creswell (2012b) breaks down reflexivity into two stages, the first of which is for the researcher to consider their past experiences from different quarters, education, family dynamics and anything else pertinent to the phenomena of research. Secondly, the researcher needs to be self-critical about how these past experiences have influenced the study process including findings, conclusions and interpretations.

Maton (2003) indicated that in the late 1980's reflexivity in the social sciences was not often actively undertaken but that by 2003, reflexivity was receiving universal approval and not being seen to be reflexive was viewed badly. This initial apathy towards reflexivity was highlighted by Woolgar (1988), they along with other authors highlighted the state of reflexivity in the social science at this time, *'in an effort to explore the ways that reflexivity has been variously ignored, evaded, pursued and celebrated.'* It has been identified by several authors that while it has been accepted that being reflexive is important there is little agreement on what being reflexive means (Lynch 2000; Finlay 2002a; Mauthner and Doucet 2003). Lynch (2000) offers an extensive but not exhaustive list of types of reflexivity, from mechanical reflexivity and substantive reflexivity to methodological reflexivity and more. Methodological reflexivity is widely advocated and focusses more on reflections on the methods used rather than the epistemological connotations of the research. This separation of reflexivity is also supported by Maton (2003, p61), *'a fully collective reflexivity requires something that, although socially produced by the field, transcends any particular position within it'*. It would seem that the cornerstone of reflexivity is that of identifying the biases of the researcher in an effort to overcome them.

Finlay (2002b) advocates starting the process of reflexivity right from the conception of the research to completion, breaking the process into the pre-research stage, data collection stage and data analysis stage. In the following section, thinking about reflexivity from a methodological stand point, I have endeavoured to place myself within each of the stages of the research process as outlined by Finlay (2002b) and to discuss the ways in which I incorporated reflexivity into each stage of the process.

4.3.1.1 Pre research stage

From its inception this research was influenced by my training as a prosthetist. Without this training and subsequent interactions with prosthetists working within Scotland I would have been unaware of the challenges that they were facing. It was these factors that allowed me

to identify a perceived problem or 'problem in waiting' in the clinical setting and which informed the development and direction of this piece of research. Working as a research assistant at the NMAHP research unit I was aware that I was isolated from other members of my profession as I was the only prosthetist working there among a number of nurses, midwives and other allied health professions. As a result, neither of my supervisors shared my clinical background so in order to maintain the clinical relevance of this piece of research I created a PhD advisory group. This was a group comprising practicing prosthetic clinicians, service managers and lecturers in the field of prosthetics and orthotics. I was able to take their advice to maintain the clinical relevance of the project, and combine it with the methodological expertise of my supervisors throughout the development of this research project.

4.3.1.2 Data collection stage

At the beginning of each interview I told each participant that I was a trained prosthetist. Some research has indicated that participants who are aware that their interviewer is a healthcare professional give more positive views of the healthcare they receive than is actually true (Smithson et al 2006). However, I made the decision for two reasons, firstly I wanted them to know how my background was linked to my interest in the topic and secondly, so that participants felt that they could talk to me about the technicalities of prosthetics if they wished to do so.

For clinicians, I felt it was important that they knew my professional background so that they did not feel that they had to 'dumb down' any of the information that they were giving me. In order to mitigate any biases that this information could have created I made it clear to patient participants that what they talked to me about was confidential and would in no way affect the care that they received. I also made them aware that I had not worked in a clinical capacity since I had graduated from University and now worked full time as a researcher. From this place of knowing, participants were able to talk to me freely, knowing that I would understand the technicalities of the care they were giving in the case of staff, and the care they were receiving in the patient interviews. I feel that I was able to explore aspects that I would not have been able to do had I not been trained as a prosthetist. Having made this decision I did also recognise that this could affect the data collected.

Critical incident technique (discussed in more detail in section 4.4) was used in interviews with the prosthetist staff group. This aimed to focus on what prosthetists actually did rather

than what they felt they should do. Participants were asked to focus on real life cases and were asked 'what' rather than 'why' questions which could have had the effect of making them defend rather than describe what they had done.

4.3.1.3 Data analysis stage

The process which was undertaken in the data analysis stage aimed at minimising the biases which I brought to the analysis. Data analysis matrices were developed through an iterative process of creation, discussion and adaptation between myself and my supervisors until we were all happy that the themes presented were representative of the data. During the analysis of the data I had to be aware of several biases which I had when undertaking this research. An important one of these was that I believed that participants would identify the care that they had received at Headley Court to be far superior to the care that they received from the NHS, I had to be careful not to let this influence my analysis, what I ultimately found did not meet with my pre-formed assumptions. I was also aware that as a prosthetist I must not infer more from the data than was actually there, this was particularly difficult when reading sections of the data and realising that in some cases my interruptions had perhaps prevented the participant from completing an important sentence, I had to be careful in these cases not to try and 'fill in the blanks'. In relation to this point, during the analysis of the data I included a substantial number of direct quotes in order to evidence the trustworthiness of the meaning that I was taking from the data.

4.4 Design

In order to understand the prosthetic prescription decision, the perspectives of a number of different groups were required: in particular prosthetists, members of the wider multi-disciplinary team and patients receiving prosthetic care. To capture these very different perspectives two distinct qualitative studies were conducted. Semi structured interviews were used with all participants in both studies, methodological issues relating to these are discussed below, (topic guides for each study can be found in Appendix 3).

With the prosthetist group verbal protocol techniques were used in order to elicit data particular to the decision making process in prosthetic prescription. A key problem for decision making research has been to elicit factors underpinning decisions. While the endpoint of the decision may be evident the thinking behind it may be unclear, even to the decision maker themselves. Payne et al (1978) highlighted that prior decision making

research had focussed on data which reflected the end product of a decision such as rankings, ratings or proportions rather than the process the decision maker used to make a judgement or decision. This point was also made by Pitz (1977) who intimated that if someone was interested in how a subject reached a decision then a technique had to be derived in order to explore their pre-decisional behaviour. A number of methods of exploring this pre-decisional behaviour were presented by Payne et al (1978). These methods included verbal protocols which in their simplest form ask that the subject 'to think aloud' by giving a verbal account while involved in the decision task. Verbal protocols have existed in the study of problem solving for many years (Duncker and Lees 1945) but were not used within behavioural research including decision making until much later (Newell and Simon 1972). Now, in behavioural decision research verbal protocols are one of the most widely used process tracing methods (Payne et al 1993; Svenson 1979). Verbal protocols aim to gain an accurate account of the subjects ongoing thought process from their perspective to give an insight into their cognitive process during the decision making task (Svenson 1989).

Verbal protocols can be either simultaneous or retrospective in relation to the cognitive process that they are exploring (Svenson 1979; Kuusela and Pallab 2000). More commonly simultaneous verbal protocols are known as concurrent. Concurrent protocols ask the subject to verbalise any thoughts that occur during the decision task whereas retrospective protocols are taken after the decision task has been completed, both types of protocols have their advantages and disadvantages. The benefit of concurrent protocols are that they are happening at the time that the cognitive process of interest is occurring and as such are more likely to provide accurate and valid descriptions of the cognitive process as it occurs (Ericsson and Simon 1980; Kuusela and Pallab 2000). The disadvantages include taking the focus away from the primary task, slowing down and interfering with the decision process (Russo et al 1989; Van Den Haak et al 2003). Additionally, in slowing down the process it is thought that this allows the subject longer to consider the decision task and interfering with the natural cognitive process allowing them to do more information processing than they would have without verbalising the process (Biehal and Chakravarti 1989). Retrospective protocols avoid interfering with the decision making process but are disadvantaged by the fact that they can be inaccurate as they require that the process of interest to be remembered and relayed and they can be subject to biases (Ericsson and Simon 1980; Svenson 1989; Harte et al 1994).

Within the prosthetist group retrospective protocols were used for a number of reasons discussed below. It was recognised that the prosthetic prescription process does not occur

over a single interaction but over a series of interactions over a period of time. Therefore the required data could not have been captured in a single session using concurrent protocols. This was anticipated to create issues from both a logistical and ethical perspective, several sessions using concurrent protocols would have had to have been used in order to collect data on a single decision making process, this was not considered to be feasible. From an ethical perspective it was considered that asking patients to have a researcher in a number of their appointments over a period of their rehabilitation could have been considered unacceptable. Additionally there is the consideration of the 'observer's paradox' (Labov 1972) which suggests that the act of observation can have an influence on the data which is being collected (Sarangi 2013). For these reasons a retrospective protocol method was chosen.

The retrospective protocol method which was chosen was that of critical incident technique (CIT). In this technique participants are asked to recall cases which clearly illustrate the characteristics of the decision task, specifically, cases which have required clinical judgement to provide an appropriate prosthetic prescription. It was intended that three to four such cases focussing on a range of patients would be elicited from each prosthetist participant. These are 'critical incidents'. CIT was highlighted as a method which could be used to investigate varied aspects of clinical practice by Kemppainen (2000) and has since been used in a variety of healthcare studies (Runeson et al 2001). CIT uses clinicians as 'observers' in that they report the case factors influencing the decision on what to prescribe. The technique uses 'what' type of questions rather than 'why', this lessens the possibility of bias as they only have to say what they did in a specific case and are not being asked to justify their actions. Further, participants are asked to report on memorable and specific cases in which it was clear that they needed to take a certain course of action. The details of such cases are not easily forgotten. When full details are given, it may be assumed that the information being recalled by the participants is accurate (Flanagan 1954) while vague reports which lack detail suggest that the incident is not well remembered and may be incorrect. The topic guide for prosthetists with embedded CIT can be found in Appendix 3.

During initial interviews with prosthetists it became clear that they were rarely able to identify single cases to discuss using the CIT methods. However, asking them to think about certain categories of cases acted as a prompt for the prosthetists and worked well in helping them to start thinking about their decision making in the prescription process. This perceived failure of capturing CIT cases was discussed with both supervisors. The decision was made

to continue to use the same topic guide for subsequent interviews as initial interviews had shown that it acted well in eliciting rich data from prosthetist participants. While these prosthetist interviews aimed to focus on the prescription process for only traumatic prosthetic patients, the clinicians who were interviewed often used non-traumatic cases to explain and draw comparisons from. During their general discussion prosthetists often failed to distinguish between traumatic and non-traumatic cases.

Interviews in general are a widely used method of qualitative data collection and are considered to result in rich multi-faceted data. Interviews are particularly commonly used if the researchers' objectives are mainly exploratory, whether this exploration is of the participant's attitudes or opinions then interviews can be a good approach. In the case of clinicians, the use of interviews can also be valuable over the use of questionnaires. Questionnaires can be seen to limit exploration within the researchers' areas of interest as well as limiting options of choice for the respondent. It has also been found that respondents can be reticent to committing their opinions and feelings to paper (Gray 2009b).

Focus groups can be used in a similar way and have been reported that in some cases the data gathered can be richer due to the discussion between members of the group uncovering further data. In a well facilitated focus group the researcher should only participate by gently guiding the discussion towards particular topics of interest. Discussion between members of the group is also likely to uncover further topics of interest that may not have been fully realised previously. In this project the decision was taken to use one to one interviews rather than focus groups due to the mix of clinicians and the mix of experience levels of individual clinicians. In addition, with the small population of participants available, and wide geographical distribution, it was thought that it would be difficult to get enough participants for enough meaningful focus groups. One to one interviews were used in order to create an environment where the clinician participants felt comfortable in expressing their views without expressing these to the rest of their peers. It is also often difficult for clinicians to find time to participate in focus groups. It was likely that these would have needed to be conducted locally which would have resulted in colleagues being in the same group, perhaps with line managers which may have limited their ability to talk openly.

Semi-structured interviews were chosen for interviews with members of the multi-professional care teams and the patient groups as the research questions dictated that

there were specific topics that I wanted to cover in each of the interviews. Similarly, using a structured interview approach would have been too prescriptive, and may have prevented me from exploring further topics and areas of interest to participants if they had not been included in the initial interview schedule. The use of semi-structured interviews allowed me to prompt the participants to further explore areas of interest as they arose throughout the interview process. With the lack of previous research in this area combined with the exploratory nature of the project to establish a baseline for future prosthetics decision making research, interviews were the chosen method of data collection.

Within healthcare research one of the most economical methods of capturing patients evaluations of healthcare is using questionnaires and these are widely used in the gathering of information on patients' satisfaction with the healthcare services they receive (Bowling 2009b). Survey methods in this area have been criticised due to the multiple dimensions of satisfaction which can lead to the lack of specificity of the data gathered and therefore its ability to identify precise areas of patient satisfaction and dissatisfaction. In order to combat this shortcoming of survey design, surveys can be supplemented with additional open ended questions. Further than this a mixed methods approach can be taken where the quantitative survey data can be supplemented with qualitative focus groups or in depth interviews with a sub-sample of the population of interest.

For this study, with the lack of prior research in the area there was not enough data available on the study sample group to create a survey which would be able to precisely measure the aspects of prosthetic healthcare delivery of interest. Bowling (1997) highlighted that qualitative techniques are essential in the early phases of questionnaire design. In addition the size of both of the populations of interest in this study was small and so did not lend themselves to enquiry using a survey design.

For these reasons semi-structured interviews were chosen as the data collection method for participants from each of the patient participant groups. Focus groups were not considered viable within these groups due to the small number of potential participants throughout Scotland and the rest of the UK, particularly in the case of amputee veteran group. In addition to the small numbers, the geographical spread of these patients was large, covering the majority of Scotland and a wide catchment area in England. Arranging focus groups taking into account these factors was not considered to be feasible. Furthermore, potential participants could have been at different stages in their prosthetic

rehabilitation, and some may not have felt ready to share their experiences with others. It would also have been necessary to conduct separate focus groups with civilian and veteran amputees as sharing information on the potential 'gold standard' care and prostheses provided by the MOD could have been upsetting for NHS patients to hear or it could have affected their perceptions of the NHS care they received.

4.4.1 Setting

The setting for both studies was initially three of the NHS disablement services centres (DSCs) in Scotland. After encountering difficulties in recruiting a sufficient number of amputee veterans through these three centres a further study site was added. This fourth site was also an NHS DSC one of nine centres who provide specialist care for amputee veterans in England.

4.4.2 Study 1

4.4.2.1 Aim

The aim of study one was to explore the barriers and facilitators for providing prosthetic care to trauma amputees within the NHS in Scotland. In particular civilian trauma amputees and current and anticipated amputee veterans within the NHS. It also aimed to explore the factors affecting the decision making process in prosthetic prescription for these groups of patients.

4.4.2.2 Research questions specific to this study

1. What are the issues and drivers for prosthetic service delivery for trauma amputees, in particular, current and anticipated service related amputees?
2. What factors (clinical and non-clinical) are used in the judgements and decision making of prosthetists during prosthetic prescription for civilian trauma amputees and service attributable amputees?

I was ultimately unable to answer the first research questions, data collected relating to this research question was discussed in section 3.6.

4.4.2.3 Sample

Qualitative research methods aim to understand complex phenomena and can be used to generate hypotheses or potential explanations for certain phenomena. The study sampling strategies reflect the desire to gather in-depth information about a small population of interest rather than a little information about a larger population. The findings of qualitative

research are not designed to be generalisable to a wider population. Reflecting this premise, this study used a purposive approach to sampling. Kelly (2013) described purposive sampling as being used to select participants who are most likely to provide ‘appropriate and useful information’. Purposive sampling techniques within each of the target groups (outlined below) were used in order to capture as diverse a range of perspectives as possible. Figure 10 shows the intended participant sample for study one, the setting from which they were recruited and the number of participants who took part from each of the target groups.

Target participant groups:-

1. NHS prosthetists involved in the prosthetic rehabilitation of trauma amputees
2. NHS physiotherapists involved in the prosthetic rehabilitation of amputees
3. NHS rehabilitation consultants involved in the prosthetic rehabilitation of amputees
4. NHS prosthetic service managers

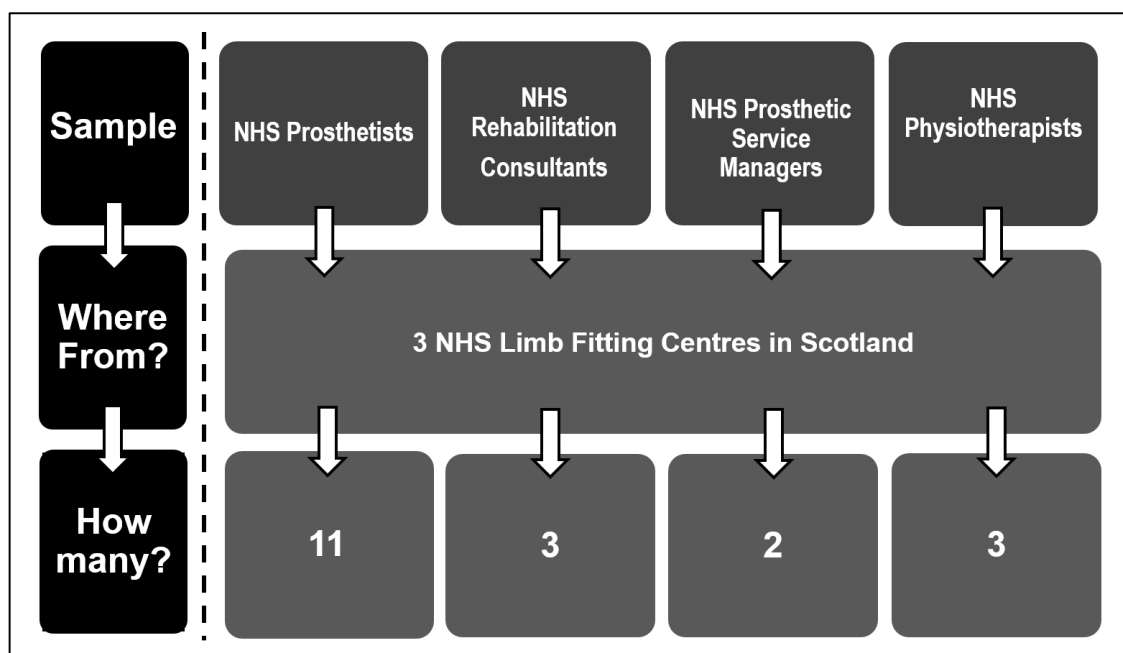


Figure 10: Study 1 sample diagram

4.4.2.4 Recruitment

Recruitment for study one was facilitated by the lead prosthetist at two of the participating limb fitting centres in Scotland and by a senior prosthetist in the third. The local contact at each centre was sent enough participant information packs for each of the eligible clinical and managerial staff within their centre. Eligibility was assessed by the local contact in

each centre based on the criteria provided by me. Information packs were then distributed by the local contact to eligible participants. Each pack contained a covering letter, a participant information sheet (PIS) and pre-paid return envelope. At the end of the PIS there was an attached return slip which interested eligible staff were invited to complete and return to the me in the pre-paid return envelope. This slip enabled the participant to provide me with their contact details. This information was then used to contact interested staff members to organise a mutually convenient time and location to conduct the research interview. Individualised PIS were created for each staff group, an example of one of the staff PIS can be found in Appendix 4. This method was used to recruit prosthetists, rehabilitation consultant, prosthetic service managers and physiotherapist groups; however recruitment for each of these groups were not undertaken at the same time. Prosthetic service manager and physiotherapist samples were not added to the study until recruitment of the first two samples had started. The physiotherapist sample were the last to be recruited and were added when data analysis of the prosthetist and rehabilitation consultant data had been started. It was this initial data analysis of these starting groups which

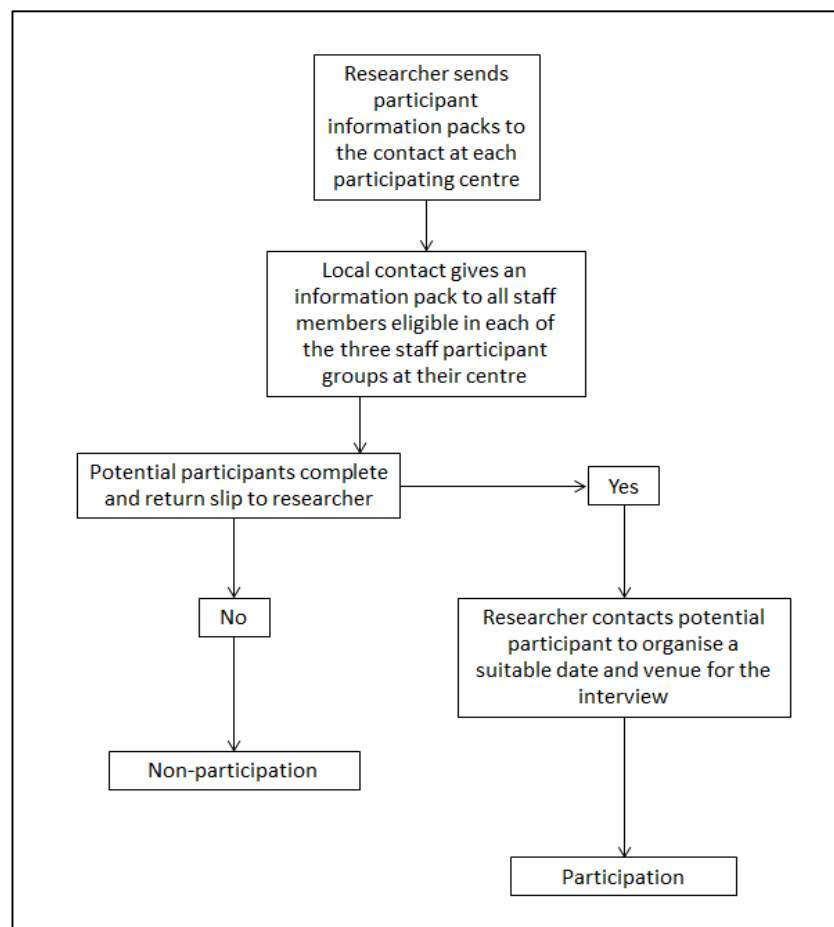


Figure 11: Staff recruitment process

informed the addition of the physiotherapist sample. Figure 11 shows a flowchart depicting the process of recruitment participant groups in Study 1. The participant groups included NHS staff with different levels of experience, however, level of experience did not affect their eligibility to participate in the study and it was made clear to them in the PIS that a decision not to participate would not adversely affect them professionally (see Appendix 4). If they did wish to participate it was made clear that all information provided would be kept confidential and any personal identifying data gathered would be carefully anonymised before use. Further information around data management can be found in section 4.6.2.

4.4.3 Study 2

4.4.3.1 Aim

The aim of study two was to explore patients' experiences of prosthetic care delivery in the UK and to explore their experiences of involvement in their prosthetic rehabilitation. In particular the decision making process around their prosthetic prescription. This study also aimed to explore the process of transition of prosthetic care from the MOD to the NHS for military amputees who suffered limb loss and subsequent discharge from the Armed Forces.

4.4.3.2 Research questions specific to this study

3. What are trauma patients' experiences of prosthetic care in the UK?
4. What are the experiences of involvement in decision making in the NHS and the MOD of traumatic civilian and service attributable amputees?
5. What are the experiences of transition of prosthetic care for those amputees moving from the MOD to the NHS?

4.4.3.3 Sample

Purposive sampling was used within the target participant groups in study two (outlined below) as discussed in section 4.4.2.3 in study one. Figure 12 outlines the same information for study two.

Target participant groups:-

1. Civilians who had undergone amputation as a result of trauma and have received prosthetic care through the NHS
2. Veterans who have undergone major limb amputation as a result of military service and have subsequently been discharged from the Armed Forces

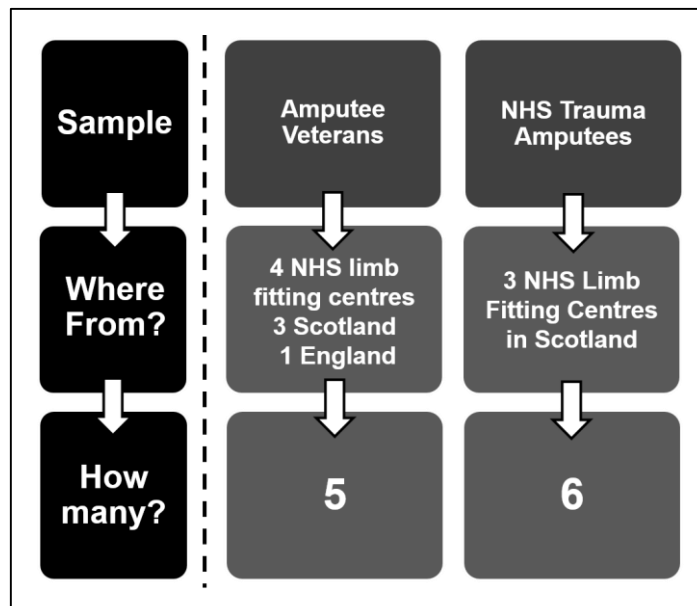


Figure 12: Study 2 sample diagram

4.4.3.4 Recruitment

Civilian group: As discussed in section 4.4.1 the setting for civilian trauma amputees was NHS prosthetic services in Scotland. Participants of this group were recruited through each of the three participating limb fitting centres in Scotland using methods similar to those used in Study 1. The local contact liaised with each of the prosthetists working within their centre to identify all eligible patients under their care. The eligibility criteria were set by me and implemented through the local contact and prosthetists at each site. The inclusion and exclusion criteria used are outlined in Table 7. I was then informed of the number of eligible participants at each site by the local contact who were then sent them the corresponding number of participant information packs. The local contact then posted participant information packs to all those eligible to participate from their centre. During the eligibility screening process clinicians were asked to pay particular attention to any diagnosis of PTSD or other mental health problems associated with their patients' trauma identified in their notes. The remainder of the recruitment process was the same as that used in study 1; eligible participants were invited to participate in the study via the PIS. If they wanted to take part they were asked to complete and return the slip from the PIS directly to me in the pre-paid return envelope provided. I then contacted them directly to organise a mutually convenient date and location for an interview to be conducted. A flowchart outlining the patient recruitment process can be seen in Figure 13.

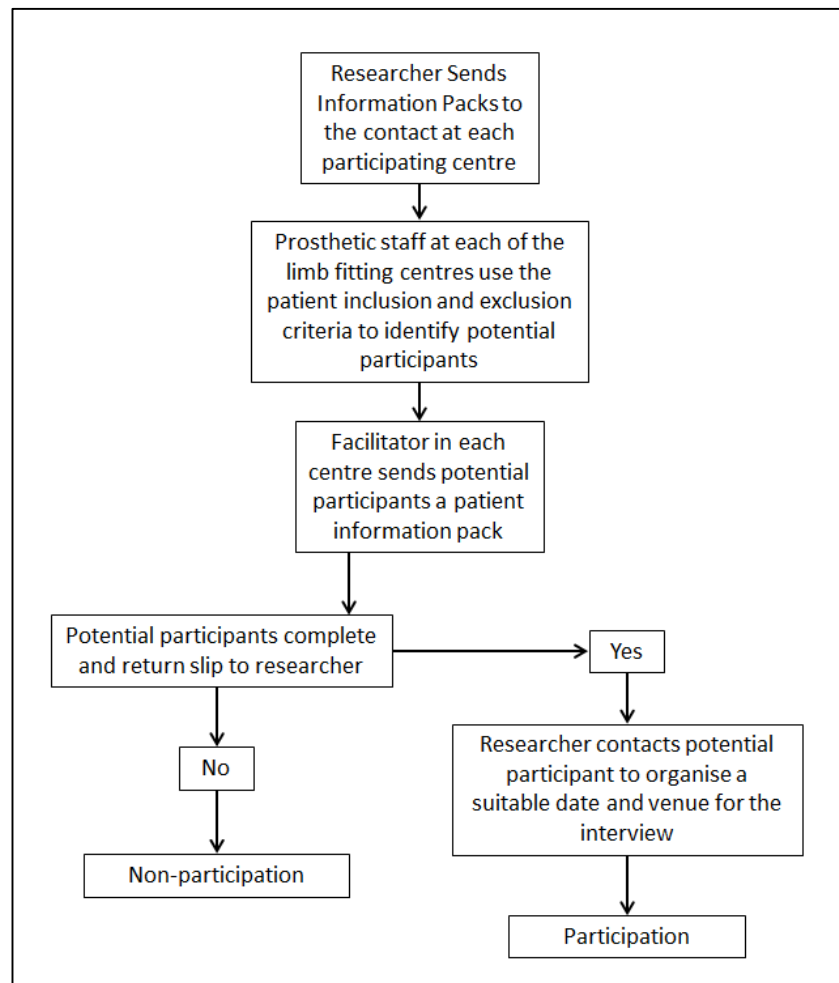


Figure 13: Patient recruitment process

Veteran group: Several recruitment strategies were considered when thinking about how to access this hard to reach group of participants. It was originally planned that the veteran group would be recruited through Blesma, The Limbless Veterans; a national charity who support service men and woman who have lost limbs or their eyesight as a result of military service. This route was pursued for a period of time, unsuccessfully, before the decision was taken that other options should be explored. More information about the problems encountered with recruiting through Blesma can be found in Appendix 2. During recruitment of civilian trauma amputees through the NHS two local contacts enquired if veteran amputees under their care were eligible to participate. Initially they were told that there was no ethical approval to recruit this sample through the NHS. Shortly after this, the decision was taken to apply for approval to recruit the veteran amputee group through the three Scottish NHS sites as I was already doing for the civilian amputee group. Over time it became clear that there were not enough amputee veterans eligible for this study based in

Scotland at that time². Conversations with clinicians working with amputee veterans outwith Scotland indicated that there was a wider interest in this piece of research and further sites which could be utilised for recruitment purposes. For these reasons a fourth NHS site was added, this one based in England. This fourth centre was also one of the designated specialist veteran prosthetic centres within the NHS in England. As such they were responsible for the care of a number of amputee veterans who had been recently discharged from the Armed Forces. It was felt that with the addition of this site that the sample target for this group could be met.

While awaiting ethical and R&D approvals to recruit this group through the NHS another strategy was used in an attempt to recruit this group. A single page invitation website was created; this was a simple website which contained a brief explanation of the project and why it was being done. It also contained outline information on the inclusion and exclusion criteria for the project. The website invited amputee veterans who felt that they were eligible to participate or who wanted to find out more to contact me for further information and possible recruitment. A screenshot of this website can be found in Appendix 5. A shortened URL for the website was created and disseminated through twitter to possible interested parties. Ultimately all civilian and veteran amputee participants were recruited through the NHS across the four sites. Table 7 shows the eligibility criteria which were used by local contacts and prosthetists during the screening process for potential participants.

These inclusion criteria were developed with a number of factors in mind. Firstly, it was desired that the amputee veteran population would have had sufficient experience of receiving prosthetic care in the MOD and NHS settings. For this reason participants were included up to 10 years from their initial injury and/or amputation. Findings from the scoping study indicated a number of years could elapse from amputation until personnel were discharged from the Armed Forces so it was important that this delay was taken into account. Civilian amputees were then matched in their inclusion criteria for time since amputation. The exclusion criteria were developed for a number of reasons. Non-English speaking participants were excluded as there was no budget for a translator to be present during the interview process or for translation to be carried out on interview transcripts. Amputees over the age of 54 were excluded as the majority of civilian trauma amputees are

² This was in part due to the Armed Forces delaying a number of personnel discharges around this time in order for these patients to be supplied with further SOTA limbs prior to discharge.

in the 18-54 year old age bracket; by excluding those over the age of 54 it enabled the civilian and amputee veteran age groups to be comparable without being too restrictive. The exclusion criteria related to a diagnosis of PTSD or trauma related mental health issues was a stipulation made by the School of Health Sciences Research Ethics Committee, details of this stipulation can be found in Appendix 6.

Table 7: Eligibility criteria for civilian and veteran amputee groups

Inclusion Criteria	Exclusion Criteria
NHS and MoD amputees who have experienced traumatic amputation of at least one arm or leg in the last 10 years.	Non-English speaking amputees
Amputee veterans who have experienced traumatic amputation of at least one arm or leg as a result of service in the last 10 years.	Amputees who have not lost their limb as a result of trauma.
Amputee veterans receiving prosthetic care in the NHS in Scotland or England.	Amputees who lost their limb/limbs as a result of trauma over 10 years ago.
	Amputees over the age of 54
	Amputees with insufficient capacity to provide informed consent
	Amputees with a diagnosis of post-traumatic stress disorder (PTSD) or other trauma related mental health issues.

Table 8 indicates the length of time between the patient participants' amputations and their interviews. Table 9 and Table 10 give demographic information for prosthetist and amputee participants respectively.

Table 8: Time from amputation to interview

Participant pseudonym	Date of accident	Date of amputation	Date of interview	Length of time from amputation to interview
Frank	2012	2012	2013	5 months
John	2010	2011	2013	2 years
Gavin	2009	2010	2013	3 years
Chris	2009	2011	2013	2 years
Ted	2002	2002	2014	12 years
Sam	2011	2011	2013	2 years
Colin	2003	2003	2013	10 years
Douglas	2011	2011	2014	3 years
Jack	2009	2010	2014	4 years
Rory	2009	2009	2014	5 years
David	1982	1982	2013	31 years

Table 9: Prosthetist participant demographic information

Item	Number
Age	
30 - 39	4
40 - 49	5
50 - 59	2
Years in practice	
<10	2
11-15	2
16-20	3
>20	4

Table 10: Amputee participant demographic information

Item	Number
Age	
20-25	3
26-30	2
31-35	1
36-40	0
41-45	2
46-50	0
51-55	2
56-60	1
Type of amputation	
Unilateral: below knee	9
Bilateral: above knee, below knee	1
Bilateral: above knee	1
Relationship status	
Married	5
Single	5
Other	1
Employment status	
Unemployed	8
Employed	3

4.5 Data Analysis

A common approach to analysing qualitative data are to follow the principles of content analysis. In content analysis inferences are made of the data through a systematic identification of classes or categories with the data. Objectivity is achieved by applying a pre-defined set of rules, *criteria of selection*, which need to be established prior to data analysis (Joffe and Yardley 2004; Gray 2013). In general, content analysis provides an explanation of the data where the importance of a comment or theme is based upon the number of times it is mentioned, i.e. the more important the concept the more often it will have appeared in the data. This type of qualitative data analysis has been criticised for being the way of doing the most 'quantitative data analysis' possible on qualitative data. Content analysis is also seen to be more deductive in its approach, by applying a set of rules to the data which were defined ahead of data analysis content analysis uses the data

to test a hypothesis rather than to allow categories or themes to arise from the data. A further criticism of content analysis is that it removes the meaning from the data by focussing on the frequency of topics within the data rather than the context within which that category is discussed. It is argued that frequency of a category in itself does not indicate the importance of what was being said about that category (Joffe and Yardley 2004).

Similarly thematic analysis is also a commonly used method of qualitative data analysis as well as being systematic in its approach. Thematic analysis is more inductive as themes are identified by the researcher going through a process of familiarisation with the data. Thematic analysis avoids some of the criticisms of content analysis in that it does not rely on the frequency of a code within the data to rank its importance (Gray 2013). In addition the context in which the code is raised can also be taken into account therefore giving more complexity and ability to theorise from the data (Joffe and Yardley 2004). What this means is that all of the data can be explored rather than the researcher making a decision on the importance of the findings based on the frequency of the concept appearing in the data. While a number of authors talk about thematic analysis as a tool within other qualitative research methods (Boyatzis 1998; Ryan and Bernard 2000; Holloway and Todres 2003), Braun and Clarke (2006) identified thematic analysis as a method in its own right. One of the benefits of thematic analysis as outlined by Braun and Clarke is that it is a method which is not constrained to use with a specific theoretical or epistemological position but is instead compatible as a method of data analysis across a spectrum of qualitative research designs. Braun and Clarke (2006) outlined a number of phases undertaken during thematic analysis, these can be found in Figure 14.

Phase	Description of the process
1. Familiarizing yourself with your data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes:	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Figure 14: Phases of thematic analysis (Braun and Clarke 2006)

Thematic analysis was used to analyse the data from both studies in this research project. Following each of the phases as outlined below and being transparent about how each

phase was achieved should increase the rigour of the data analysis, as well as providing a blueprint to other researchers. This blueprint should enable other researchers conducting analysis of the data to follow the documented process, thereby increasing validity and reducing potential subjectivity within the analysis. Reducing subjectivity or bias in the analysis can also be achieved by involving more than one person in the analysis process. I and both of my supervisors were involved in the data analysis process for both studies.

Phase 1.

I conducted all of the interviews for study one and study two. Each of the interviews recordings were sent to a private company to be transcribed verbatim. Each recording was sent for transcribing as soon after the interview had taken place as possible. I then compared the transcript to the recording, at this stage I made any corrections or addressed any queries that the transcriber had noted in the typed transcript. A number of transcripts were identified for the familiarisation process, this included six transcripts from study one. These included a cross section of transcripts in order to include members from each of the four staff groups. I also identified six transcripts from study two, again this allowed transcripts from both veteran and civilian groups to be included. A proportion of the transcripts from both studies were taken from interviews carried out at the beginning and end of the data collection process, during data collection some of the questions were adapted for subsequent interviews. The identified transcripts were read and reread and initial general notes made during this process.

Phase 2.

After I had become familiar with the twelve transcripts identified in phase one I began to create a list of codes for each transcript. These codes consisted of a list of all of the subjects or topics that the participant had talked about throughout the interview. An example of the coding process at this stage can be found in Appendix 7. Following on from the familiarisation process I constructed a preliminary set of codes for each of the studies to discuss with my supervisors.

Both supervisors were provided with copies of the six transcripts for each study, they independently created a set of initial key codes for each of the studies. These were then compared and discussed (including my own initial set of identified codes) which resulted in the revision and consolidation of an initial set of codes thought to generally reflect the key areas of concern emerging from the transcripts.

Phase 3

An on-going iterative process was also used in the development of the codes for both study datasets. In applying the initial set of codes to subsequent transcripts, new codes or revisions to existing codes were necessary. New iterations of the coding framework were discussed between myself and my supervisors until we were all satisfied that the coding frameworks were representative of the transcripts used in the familiarisation process and subsequent transcripts.

Phase 4

In phase three I spent a substantial amount of time refining the coding framework. I found that I worked in a more visual way in this phase constructing a number of different mind maps to help make sense of the codes and to construct themes across both patient and staff data sets. Several examples of different iterations of these mind maps can be found in Appendix 8. Throughout this phase the themes were refined through a number of iterations between myself and both of my supervisors. By the end of this phase I had created initial thematic frameworks in order to extract data (see Appendix 9). I was then able to begin mapping the coded data to these themes.

Phase 5

Throughout the process of mapping the coded data to the thematic framework for studies one and two the themes evolved further becoming less descriptive and more analytical. This process was conducted through a process of mapping the coded data, any issues arising were discussed with my supervisors. Through these discussions we further refined and adapted the themes and their definitions, moved them around the thematic diagram until I was happy that each of the completed thematic frameworks represented a good fit with their respective data sets.

Phase 6

Final analysis of the data was undertaken through writing up the results for each of the data sets. Chapter 6 presents the findings from the study one and Chapter 7 the findings for study two.

4.6 Ethical considerations

4.6.1 Informed consent

Within research informed consent refers to the process of gaining permission from the participant to take part in the study. Only when the participant has been provided with information concerning the process of what they must undertake in order to participate, any risks which may arise from their participation and a full explanation of the reasons for the undertaking of the study can informed consent be said to have been achieved. Informed consent makes up part of the ethical codes set out by the Nuremburg code and later the Helsinki Declaration.

To comply with these requirements, potential participants in each study were provided with a participant information sheet, copies of each of the PIS can be found in Appendix 4 and 10. Participants were given a minimum of one week in which to read the information sheet and contact me or the project sponsor should any further information be required regarding the study or if they had any other queries. On the day of the interview participants were again asked if they had received the information sheet and asked if they had any questions, if not then they were asked if they were still happy to take part in the study. If they indicated that they were then they were required to sign two copies of the consent form (see Appendix 11), one copy was kept for my records and the other they were given to keep. Participants were made aware, both in the PIS (Appendix 4 and 10) and verbally that they were able to withdraw from the study at any time, without having to justify their choice and that this would not have any effect on their medical or legal rights (in the case of patient participants) and their employment position in the future (in the case of staff participants).

4.6.2 Confidentiality and anonymity

Each interview was recorded using a portable digital recorder after receiving written informed consent from each participant. Recordings were uploaded onto a password protect computer as soon after each interview as possible, once uploaded recordings were deleted from the portable digital recorder. Recordings were transcribed verbatim and checked for accuracy when the each typed, transcribed interview was received. After checking the accuracy of each transcription I removed all identifying information from each interview transcript. All transcripts were kept on a single password protected computer, only I had full access to these documents. In the case of clinician interviews these were numbered and these numbers used to refer to them in the following data analysis. In the

case of patient transcripts each was assigned a pseudonym for the purposes of data analysis. It was made clear to all participants that all of the information that they provided during their interviews would be kept confidential and any personal identifying data gathered would be carefully anonymised before use.

4.6.3 Potential risks and safeguards against risk

4.6.3.1 *Participants*

No major management or ethical issues beyond the usual issues of confidentiality were anticipated. In the case of patients it was made explicit that any personal information would be anonymised and destroyed in accordance with the University of Stirling research governance procedures. Although it was not anticipated, it was possible that in discussing their experience of limb loss participants could become distressed. Interviews were handled sensitively to minimise this risk, however, provision was made so that if a patient became distressed by the issues raised in the interview during or directly after, they could be provided with the contact number and name of a prosthetist(s) who agreed to discuss or clarify any issues raised in the interview. In addition if patient participants required further support as a result of topics raised during the course of the interview, they could be provided with the contact details of a clinical psychologist with experience of working with people with trauma-related distress. This clinician had been identified and had agreed to act in this role prior to the start of the study.

4.6.3.2 *Researcher*

There were cases where the researcher was working as a lone worker when conducting interviews. This occurred most frequently for interviews undertaken with participants in study two. This occurred as in all but one of the cases the most convenient location for the interview was at the home of the participant. This had been anticipated before the project started and a process put in place in order to keep the researcher safe, this lone worker policy is outlined in Appendix 12. In no instances during data collections for this project was it required to implement this lone worker policy.

4.6.4 Ethical Approval

Ethical approval is required prior to carrying out research. During this process an ethics committee considers the methods and assesses them against pre-determined ethical principles. These principles exist in order to protect the research participants. Current

ethical practices are commonly linked with the resulting recommendations of the Nuremburg trials, the Nuremburg Code. The notion of informed consent, which was seen as the first 'rule' of the code is a principle which sits at the heart of current ethical practices in healthcare and practice (Shuster 1998). Current International guidelines for undertaking biomedical research on human subjects have been developed by the Council of International Organisations of Medical Sciences (CIOMS) in collaboration with the World Health Organisation (WHO) (Council for International Organizations of Medical Sciences 2002). The intended participant samples and settings for this research meant that several levels of ethical approval were required as described below.

4.6.4.1 School of Health Sciences Research Ethics Committee

All doctoral research projects registered with the School of Health Sciences at the University of Stirling must be submitted for internal ethical review and approval prior to ethical review by any external organisations. In addition, one of the target populations included veteran amputees. As it was initially planned to recruit this group through the charitable organisation Blesma, a third sector organisation NHS ethical approval was not required. Ethical approval was sought from the School of Health Science Research Ethics Committee (SHSREC) for the full project. Ethical approval was granted by SHSREC in August 2012 after minor amendments required by the committee had been made.

4.6.4.2 National Health Service Research Ethics

After receiving ethical approval from SHSREC a submission was made to the one of the NHS Research Ethics Committees based in Scotland (not identified to maintain confidentiality of participants). NHS ethical approval was required for the following participant groups; civilian trauma amputees, amputee veterans, prosthetists, service managers, rehabilitation consultants and physiotherapists. I and one PhD supervisor attended the REC meeting at which the proposal was being reviewed, at this meeting we were available to answer any questions the committee had on the protocol or any other points they wanted clarified. Approval was granted subject to minor amendments at the end of September 2012.

In addition to ethical approval research projects being carried out in the NHS also require management approval. These are known as research and development (R&D) approvals. On receipt of NHS ethical approval I began the process of applying for NHS R&D approvals. These approvals were required to gain local access and management approval to carry out

the proposed research activities within each of the four appointed NHS sites. Initial application and supporting documents were sent to the NHS Research Scotland Permissions Coordinating Centre (NRS Permissions CC) based in Aberdeen. This Centre manages the process of obtaining R&D NHS management approvals for multicentre research projects in Scotland.

On receipt of the generic project information NRS Permissions CC disseminated that to each of the centres who had been selected to host the project. Individual centres then made requests for additional information that they required directly to me. Generic forms of documentation required by the NRS Permissions CC included a research passport and a breakdown of the tasks that the research project required of staff at the hosting sites and the time that it was estimated that these tasks would take. The applications for R&D approval were started in September 2012; approval for all three sites was granted at the end of December 2012. Only when R&D approval had been granted could data collection at NHS sites be started. Throughout the project a number of amendments were made, each of these amendments were approved by NHS ethics and R&D.

5 Chapter 5 - Decision Making Overview

This research study aimed to explore how clinicians described making prosthetic judgements and decisions, focussing on their accounts of decision making in prosthetic patient cases. In addition, the research aimed to understand patients' experiences of their involvement in prosthetic care. An understanding of both decision making theories, and patient involvement literature was therefore required so that 1) the data could be adequately analysed, 2) the analysis could be adequately interpreted, and 3) the findings placed in context. This chapter provides an overview of decision making theories as well as theories of patient involvement in healthcare. The first half of this chapter gives an overview of the literature on judgments and decision making with the second half outlining some of the theories of patient involvement in healthcare.

5.1 Clinical Judgments, Decision Making, and Risk and Uncertainty

In order to understand the substantial body of literature concerned with judgment and decision making, it is first necessary to understand how judgements and decision making are defined within the context of this thesis and the role that this plays. The terms 'judgement' and 'decision' can be difficult to distinguish. An explanation of the subtle difference between a judgement and a decision is offered by Dowie as follows:

"Decision is to be contrasted with 'judgment'. It involves choosing between alternatives, whereas judgement involves the assessment of alternatives"

(Dowie 1993, p8)

In prosthetic prescription the initial assessment of the patient could be described as the judgement followed by a decision process during which the prosthetist must make a choice on the prosthetic components that they are going to prescribe for that patient.

It is important to note that decisions and judgments in the real world are often made under circumstances of uncertainty. This uncertainty commonly creates difficulties in forecasting the outcomes of different decision situations (Schultz et al 2010). In decision situations where the probabilities are objective or given, then this is defined as risk. In situations where the probabilities are subjective, this is defined as uncertainty (Wu et al 2004). In the real

world there are very few situations in which decisions or judgements can be made without risk or uncertainty (Hastie and Dawes 2001).

5.2 Normative, descriptive and prescriptive

Judgement and decision-making research has focussed on three main approaches; descriptive, normative and prescriptive. Descriptive approaches attempt to explain how people make real life judgements and decisions, normative techniques describe how people should, ideally, make judgements and decisions while prescriptive techniques aim to improve the judgements and decisions that people make (Baron 2000b). As there is as yet, little research around decision making in prosthetic care the research undertaken in this thesis used a descriptive approach.

5.3 Sub-divisions of decision making theory

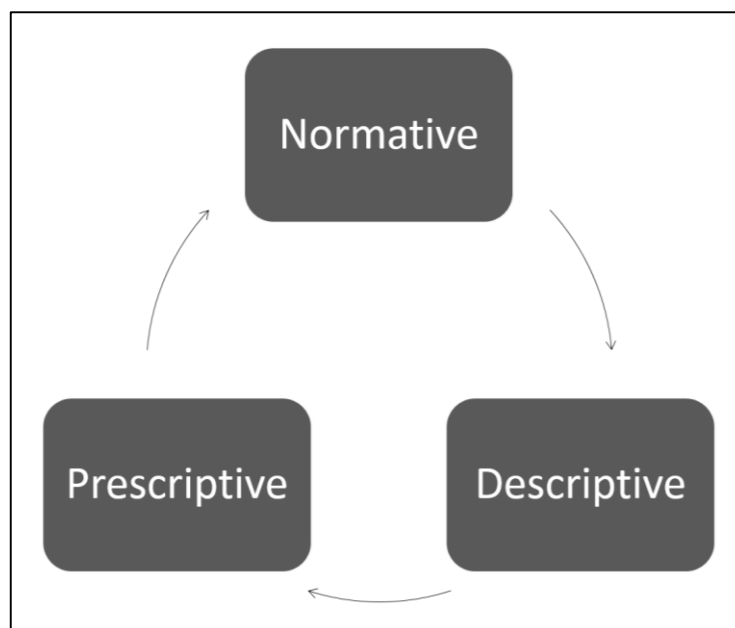


Figure 15: Interaction of the three areas of decision making theory

Decision making has been recognised as an important area of study in a number of different disciplines, including mathematics and economics, since the middle of the 18th Century. However, it remained relatively unexplored by psychologists until the middle of the 20th Century (Edwards 1954; von Neumann and Morgenstern 1945). The main body of decision making research is relatively new but large. Psychologists, in particular, have developed a number of models and theories on how people make decisions. There are two main schools

of thinking: theories of rational judgement and decision making versus models of 'non-rational' decision making (Jungermann 1983). Although more recently, there has been movement towards thinking that people most likely use a combination of the two depending on the situation and a variety of other factors (Kahneman 2011).

Despite the relative newness of decision making theory the body of literature is large. The theories of decision making can generally be split into three areas. Firstly, there are theories which derive from normative models of judgment and decision making (Baron 2007). These focus on the decisions and judgements being made in an ideal world without the constraints of time and with the availability of all the information which would enable someone to make a totally rational and well balanced decision. Secondly are the theories relating to the use of heuristics (Keren and Teigen 2007); these theories suggest that decisions are made using a set of 'rules of thumb'. Some of these theories directly oppose the normative theories of decision making and their proponents believe that normative theories of decision making have no place in the real world (Gigerenzer 2007). It has been said that the use of heuristics in decision making means making a trade-off, the trade-off which is commonly cited is that the reduction in effort results in a reduction in accuracy (Payne et al 1993; Shah and Oppenheimer 2008). However, other decision making theorists argue that such trade-offs are not always the case. We have evolved to use heuristics to allow us to make fast and good decisions in the majority of our day to day tasks. In their review Gigerenzer and Gaissmaier (2011) used the following definition of a heuristic;

"A heuristic is a strategy that ignores part of the information, with the goal of making decisions more quickly, frugally, and/or accurately than more complex methods."

(Gigerenzer and Gaissmaier 2011, p454)

The addition of increased accuracy in the definition is a more recent shift in the field of heuristics research (Brighton and Gigerenzer 2008; Gigerenzer and Brighton 2009; Marewski et al 2010).

Thirdly, and most recently, are the theories of decision making that suggest that humans use a combination of rational and non-rational decision making in their day to day lives and that it is the specific task that determines which or how these are used. These include dual

processing theory (Sloman 1996) and cognitive continuum theory (Hamm 1988; Hammond 1996). Key theories relating each of these three categories will now be discussed in turn.

5.3.1 Theories of rational decision making

Expected utility theory (EUT) is based in the mathematical and philosophical theories first proposed by von Neumann and Morgenstern (1945). Models of rational judgement are most commonly based on this normative theory. Expected utility theory is concerned with decisions under uncertainty. It is founded on the premise that the overall utility of an option in the decision making process is the expected utility of the option multiplied by the probability of that outcome. In turn, summing the expected utility across each of the possible outcomes, the one with the highest expected utility is considered to be the 'right' or 'rational' decision (Baron 2000a). Expected utility theory requires a full understanding of the background mathematical concepts of probability and enough information on each of the alternatives to be able to assess their utility. Expected utility theory as outlined by von Neumann and Morgenstern is a purely mathematical model which suggested that decision making followed a number of key principles:

1. The decision maker will make a choice between the alternatives following the rules of rational choice.
2. It is possible that they can assign a numerical figure to each of the possible outcomes or consequences; this is termed as the decision makers' utility that consequence.
3. The expected utility is calculated by summing the possible utilities and weighting them against the probability of that outcome.
4. The option chosen by the decision maker will be the one with the highest expected utility (Hastie and Dawes 2001)

Utilitarianism takes EUT further and proposes that the 'better' decision is the one that benefits the most people (Baron 2007). In utilitarianism the overall good for the population is the sum of individual utilities where individual utilities are calculated using expected utility theory (Broome 1991). The difference between the two lies in probabilities, in expected utility theory, the utility is weighted against the probability of that outcome, however, in utilitarianism the expected utility for each person is weighted equally. This additive approach illustrates the inextricable link of these two theories (Baron 2007). If you adhere to the theory of utilitarianism then you must also adhere to the theory of EUT as it is an extension of this theory.

A further extension of expected utility theory is that of multi-attribute utility theory (MAUT). As with both of the above theories MAUT adheres to the same principles of maximisation that are seen in expected utility theory and utilitarianism. However, MAUT is a theory which considers situations where the alternatives in the decision can have an impact on multiple attributes (Sarin 2001). In the MAUT model the decision begins with the identification of the choice options and their associated attributes. This is then followed with an assessment of each of the identified attributes relative importance. Each attribute is then taken and evaluated against each option to create 'single attribute utilities' which are then combined according to their corresponding attribute weights, this calculation provides the overall utility of each option (Baron 2007).

There are criticisms of these early normative theories of decision making as it is understood that decisions can often not be made with this level of cognitive involvement. There are a number of reasons for this including the presence of time pressure in the decision situation, a lack of information allowing an assessment of probability and utility or a combination of these two things. Economist Herbert Simon recognised some of these criticisms and presented his theory of bounded rationality to redress some of these issues. In his paper titled 'A Behaviour Model of Choice' Simon (1955) suggested that rational choice as modelled on 'economic man' would require rethinking and remodelling when taking into account the organism i.e. humans that are making decisions in the context of the world environment. He suggested that this reassessment of the established normative theories of decision making was required when considering humans with restricted access to full information and computational capabilities (Simon 1955). Bounded rationality explores the idea that it is not knowledge which is preventing humans from making completely rational decisions in the form of theories such as expected utility theory but other constraints including cognitive capacity, time and resources.

5.3.2 Heuristics

Heuristic theories indicate that decisions are made using a set of cognitive 'rules of thumb' (Tversky and Kahneman 1974). While the normative theories of decision making within psychology arose in the 1950's, heuristics emerged from the work of (Tversky and Kahneman 1974), their heuristics and biases approach resulted in a descriptive theory of judgement. They suggested that judgements made in the real world do not follow the rules of probability on which rational theories are based. These theories also take into account

the constraints of human cognitive capacity as well as the constraints of making numerous decisions on a daily basis in a world filled with risk and uncertainty. There are three main heuristics which have been widely tested and accepted: representativeness, availability and anchoring, and adjustment. The body of research regarding heuristics states that each of these 'shortcuts' in decision making produces a number of biases or 'errors' in decision making and judgement (Tversky and Kahneman 1974).

5.3.2.1 Representativeness

Using this heuristic people are described as evaluating the similarity of objects and categorising them based around their personal knowledge of the stereotypes of that category. Someone using this heuristic is said to evaluate the probability of an uncertain event or sample based on whether or not it is; "(i) similar in essential properties to its parent population; and (ii) reflects the salient features of the process by which it is generated" (Kahneman and Tversky 1974). For example, a person will be judged to be part of a certain group based on the representativeness, or similarity, of their characteristics to the decision makers' stereotype of that group. As with all heuristics there are a number of biases which are associated with representativeness, these include base rate neglect, belief in the law of small numbers and misconceptions of chance. Base rate neglect describes the situation where people fail to take into account the base rate when estimating probability. Tversky and Kahneman (1974) use the example of a group of subjects asked to identify the probability of a member of a population belonging to one of two professional groups, in a population of 100, containing a 70/30 split in each direction in two separate examples. In addition to this information the subjects were given a description of this group member. They were then asked to identify the probability of that individual belonging to each of the professional groups. Using probabilities the odds should be .7 and .3 in the first example and .3 and .7 in the second. The odds that the description of the person belongs to a lawyer should be higher in the population of 70 lawyers and 30 engineers and vice versa in the other population, however the findings of this experiment shows that the subjects group ignored the base rate and instead used their knowledge of stereotypes to identify the probability that the individual belonged to one professional group over the other (Tversky and Kahneman 1974). The law of small numbers indicates a situation whereby subjects consider small samples to be far more representative of the general population than they should. What this means is that researchers for example can overstate the applicability of their findings from a small population to that of the whole population that they were studying. This is described as an example of people not using the fundamental principles of statistics

in their intuitions (Tversky and Kahneman 1974). Thirdly are misconceptions of chance which describes the judgement error by which people expect that a short randomly generated sequence will reflect the characteristics of a large randomly generated sequence. For example people may expect that in a series of six tosses of a coin that the sequence H-T-H-T-T-H is more likely than the sequence H-H-H-T-T-T or H-H-H-H-T-H. This is an example of a misconception of chance, people tend to feel that a short sequence should have the same characteristics long randomly selected sequence. However, this is not the case, a short randomly selected sequences, or a section of a larger randomly selected sequence, has different characteristics to the sequence as a whole (Tversky and Kahneman 1974).

5.3.2.2 *Availability*

The availability heuristic occurs in situations where people assess the probability of a certain event by the ease with which they can recall instances of such an event. Availability is useful for assessing the frequency or probability because usually it is easier to recall an event which happens often and less easy to recall a rarer event. However, availability is affected by further factors than frequency and probability and as a result can lead to anticipated biases (Tversky and Kahneman 1974; Keren and Teigen 2007). Where representativeness can be seen as a model of judgement based on similarity, availability is a model which evaluates probability according to ease that an event can be retrieved from memory (Keren and Teigen 2007). Using the availability heuristic people tend to weigh their judgements more heavily towards new information for example using the most recent news available thus biasing their opinions. Hastie and Daws (2010) discussed availability as a commonly used heuristic but illustrated (in common with other heuristics) that it cannot always be relied upon. For example an event which has received more publicity may be interpreted as being an event with a higher probability of occurring as people would have had more media exposure to that event (Gigerenzer 2006). Using this bias we might consider that murder is more common than suicide because suicides of little known people are rarely reported in the media whereas murders are commonly reported irrespective of the identity of the victim (Hastie and Dawes 2001). Structural availability is the bias that occurs when using frequency to identify the probability of an event or occurrence because an individual's experiences may not be representative of the occurrence of that event in the population as a whole. For example a prosthetist working only with upper limb prosthetic patients might consider the probability of the occurrence of an upper limb amputation as being

disproportionately high in the general amputee population because in their day to day clinical experience cases of upper limb cases are high.

5.3.2.3 Anchoring and Adjustment

This is the third of what have been described as Tversky and Kahneman's canonical heuristics (Keren and Teigen 2007). In the anchoring and adjustment heuristic people are said to make judgements influenced by an initial suggestion, usually made by an external source. It has been found that this suggestion acts as a starting point or an 'anchor' for the judgment and adjustment is made from that starting point (Keren and Teigen 2007). Anchoring and adjustment reflects the early findings of Slovic and Lichtenstein (1971, p712) around 'starting point and adjustment strategies', which they considered to be a cognitive shortcut which enabled the person making the judgment to reduce their mental drain by averaging and weighting multiple dimensions in one go. Using this process they found that the judgements correlated with the starting point and not with the 'right judgement'. They concluded that the adjustments made during this process were commonly insufficient, thus creating bias in the judgements made. Unlike representativeness and availability the mechanisms of this process are not known. The research of Epley and Gilovich (2006) suggests that the reason for the difficulties in identifying the mechanisms of this heuristic is that there are two distinct paradigms within adjustment and anchoring. The first that people are using their own anchors and the second that they are using the previously considered outside anchors, in each of these cases people make judgements in slightly different ways influenced by the origin of their anchor (Epley 2004; Epley and Gilovich 2004). Quattrone et al (1981) theorised that adjustments vary insufficiently from the anchor because people stop adjusting when their judgment reaches a value which reaches an inherent range of believable values. The findings of Epley and Gilovich (2006) supported this theory and also identified that the adjustment was a process requiring effort. They concluded that in order to reduce the size of this bias there had to be an increase in a person's willingness or ability to find more specific estimates.

Heuristics offer an argument against the normative theories of decision making, such as expected utility theory. As normative theories, expected utility theory and other theories of rational decision making are intended to be the 'gold standard' with departures from making decisions in these ways indicating errors in the decision making process. The body of heuristics and biases research, which is descriptive, accepts that the methods of decision making described are quick and provide people with ways of making judgments while

reducing the cognitive load that they require. This body of research and its authors are credited as forming the beginning of the academic field of behavioural economics. Critics of the heuristics and biases research have suggested that it is not a complete model of probability judgment and they ignore problem solving heuristics by focussing on automatic rather than deliberate and conscious (Fiedler 1983; Lopes 1991; Gigerenzer and Todd 1999). Kahneman himself identified that while heuristics research has focussed heavily on the negative aspects of these cognitive shortcuts, there are plenty of positives. More recently theories have emerged which seem to accept that a human is not totally rational or non-rational but that a combination of the two coexist in day to day life and that one or other type of decision making will be used depending on the task. Some of these theories are discussed below.

5.3.3 Theories combining rational and non-rational decision making

The two major proponents of decision making theory which have been discussed above are polarised in their view of how humans make decisions. They suggest that a person either makes a decision using a rational process (normative theories) or they are non-rational, making judgements simply using a series of cognitive shortcuts (heuristics and biases). More recently it has been proposed, even by one of the founders of the heuristics and bias research programme, that this is an oversimplification of what humans as complex beings are doing (Kahneman 2011). From this perspective a number of theories have emerged which suggest that humans use a combination (Hamm 1988) of rational and non-rational methods of judgments and decision making depending on a number of different factors.

5.3.3.1 *Dual process theory*

Dual process theory is based on the premise that humans use two different methods of decision making in tandem, with one complementing the other (Sloman 1996). In dual process theory System 1 (S1) denotes the fast, intuitive and automatic decision making whereas System 2 is analytical, rule based and slow. It has been suggested that these two systems may be neurally differentiated (Goel et al 2000). In this theory S2 is thought to have a supervisory and adjusting role over S1 and when necessary S2 thinking can override that of S1.

Paley et al (2007) indicated that within in the context of nursing research there was a feeling of partnership between N1 and N2 (S1 and S2 extrapolated to the setting of nursing) through the use of terms such as 'integrating', 'balancing' and 'harmonising' when talking about

evidence based practice (Shaughnessy et al 1998; Haynes et al 2002; Kitson 2002). Grove et al (2000) conducted a review of 136 studies within the field of medicine, psychiatry and psychology of which only eight studies showed that among experts, clinical judgement surpassed empirically derived statistical prediction rules (SPRs), Paley et al (2007) used these findings as an indication that the equal partnership of N1/N2 seems not to apply. They concluded that these findings were an empirical indicator that, as seen in dual process theory, S2/N2 monitors S1/N1 within nursing decision making. They also highlighted that SPRs are not available for every decision that needs to be made in a clinical encounter but that their use is on the increase in the form of decision aids and decision support tools (Garg et al 2005). While decision support tools can be seen to improve decision making, not enough research has been carried out in fields such as prosthetics to inform the development of such a tool to aid prescription decisions.

5.3.3.2 *Cognitive continuum theory*

The cognitive continuum theory works on the premise that we make decisions on a sliding scale appropriate to the particular decision making situation. At one end of the continuum lies intuitive thought which consists of rapid and unconscious data processing using a series of cues, at the other end is analytical thinking, which is a slow, conscious and consistent process (Dhami and Thomson 2012) see Figure 16. Intuition is moderately accurate whereas analysis is generally quite accurate (Hamm 1988). Hamm (1988) described how in this theory tasks are placed on a continuum, where they are placed is dictated by the features of the task and how those features impact the mode of cognition that the thinker will use in that task. What this continuum indicates is that judgements decisions are usually not totally intuitive or analytical but sit somewhere on the 'continuum' between the two, where the decision task sits on the continuum will indicate the cognitive load required to achieve it. Three factors are said to affect the most appropriate cognitive mode for a task, 'the structure of the task, the number of information cues and the time available to make the judgement or decisions (Thompson and Dowding 2002).

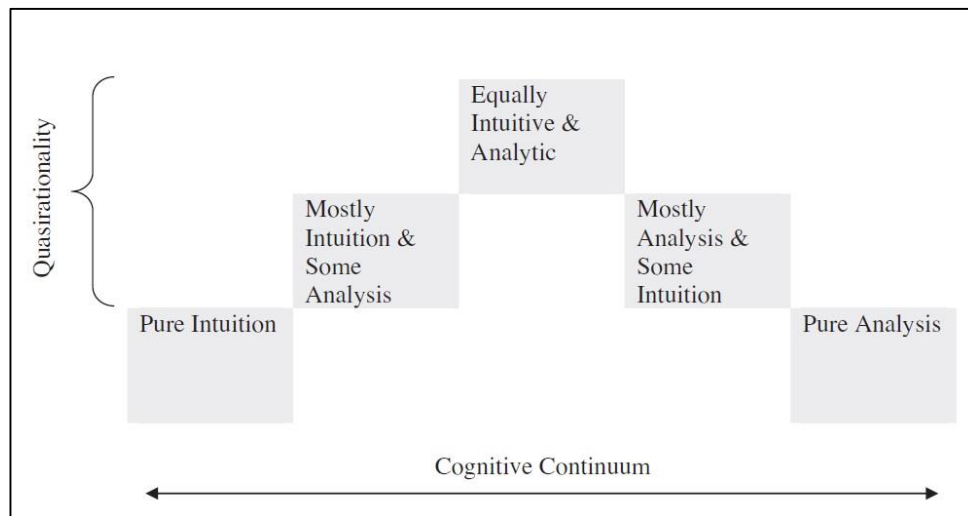


Figure 16: Models of cognition along the cognitive continuum (Dhimi and Thomson 2012)

5.4 The expert decision maker

The work of Shanteau (1987) highlighted a number of psychological studies which showed the failures of the expert decision maker (Oskamp 1962; Slovic 1969; Einhorn 1974). Shanteau's research looked at investigating the competence rather than incompetence of expert decision makers. Through his work he was able to identify some common characteristics of experts for example; they have highly developed perceptual and attentional abilities, they have a sense of what is relevant and irrelevant in a decision situation, they can simplify complex problems, they can effectively communicate their expertise to others (Shanteau 1987). Dreyfus and Dreyfus (1986) proposed that in order to become an expert we have to go through a five stage process of skill acquisition. Each of these five stages denote a different way that an individual approaches a situation, these stages were named, novice, advanced beginner, competent, proficient and expert. This model indicates that a novice required to use a structure and analytical approach to a task, whereas an expert is defined as someone who does not have to work at solving problems and has no need to be aware of the process which has occurred to solve that problem. Thus the expert uses intuition as their cognitive model. The amount of intuition used increases at each of the stages in this process (Dreyfus and Dreyfus 1986). This model has been used to study the skill acquisition of student nurses in a series of three studies (Benner 1982; Benner et al 1992; Benner 2004). Each of these studies used both interviews to explore nurses' narrative accounts of memorable clinical situations and observational methods with nurses with a range of skills levels. Their skill levels were then mapped

against the Dreyfus model of skill acquisition. They found that the model was both descriptive and prescriptive of the stages of skill acquisition in nursing practice (Benner 2004). In addition Benner indicates that this model enabled those participating to articulate the knowledge and skill embedded in nurse practicing.

The novice to expert model proposed by Dreyfus and Dreyfus (1986) differs from the theory of dual processing (Sloman 1996) that poses that humans use both rational and non-rational models dependent on the task. Instead novice to expert indicates that rational and process dependent decision making only occurs in the domain of the less experienced, i.e. the novice and is not present in experts. The novice to expert theory seems to more closely mirror the premise of the cognitive continuum theory, that intuitive decisions are more highly associated with greater levels of experience of the decision maker. Where the model of novice to expert and cognitive continuum differs is the quality of the decision made, cognitive continuum indicates that decisions using intuition are less precise whereas novice to expert seems to highly value the use of intuition by experts.

5.5 Patient Involvement in their healthcare

When considering judgements and decision making of clinicians in 'real world' healthcare settings, such as prosthetic care, the other 'players' in the process must also be discussed. This study primarily involves considering what role patients play in these processes.

5.5.1 Background of patient involvement in healthcare

The involvement of patients in their healthcare can be seen in historical accounts of the clinical encounter. May and Mead (1999) presented a chapter on 'patient centeredness', looking firstly at the history of this complex concept, and where it sits within modern healthcare delivery. For historical accounts they look at two influential theses from historical sociology (Jewson 1976; Armstrong 1982). The former highlighted the loss of the 'patient as person' towards the end of the 18th Century and the beginning of the 19th, and the latter discussing the rediscovery of this ideal in the interwar years. Jewson (1976) talked about the consideration of 'the person as a whole' disappearing within medical practice to be replaced by a focus on diseases and bodily malfunctions. He reported that the beginning of the 19th century saw the patients' experience of their disease or illness being demoted to a secondary sign where it had previously been the essence of the illness and its treatment (Jewson 1976). Armstrong (1982) showed that historical ideas of medicine in the 19th century could be seen to move in the 20th century from the patient being seen as a passive

recipient of care in the consultation to a position where they are considered as a negotiating participant. During the interwar years it began to be argued that the patients' personality had an influence on their compliance and therefore could play a role in their recovery. This link between the patient's psyche and their ill health grew in importance at this time (Brackenbury 1935; Shorter 1998). Brackenbury (1935) stated that it was not just the body that was sick but the whole person. What was also new about Brackenbury's perspective was that he was not talking about care in hospitals, which subsequent work such as Jewson (1976) focussed on, but was including the realm of general practitioners. For May and Mead (1999) this meant that there should be no aspect of the patient that was considered irrelevant to the medical care of that patient, and that the doctor themselves could, through their interaction with the patient, block the patients improved health. This was at odds to the previously held view that it was only the patient which could inhibit recovery in terms of compliance.

The place of the patient as central to the outcome of the clinical encounter in the primary care setting is seen in the work of Balint in the 1940's and 50's. He viewed the clinical encounter itself as therapeutic (Balint 1955; Balint 1965). This work further separated the practice of GP's and hospital doctors and saw not only the whole patient but also the patient within their wider social context. May and Mead (1999) see this new perspective of the clinical encounter as being the basis of subsequent medical education and literature in the field.

Research focussed on models of healthcare interaction based on paternalistic adherence and compliance has highlighted the limitations of this model (Vermeire et al 2001; DiMatteo 2004). There is an increasing awareness of their limitations in their application to healthcare relationships (Bissell et al 2004). Suggestions of a pharmaceutical working party (Blenkinsopp et al 1997) were that patient-clinician interaction should not be viewed only in terms of adherence and compliance to treatment (Blenkinsopp et al 1997). Instead they considered that healthcare relationships could be understood as a meeting of expertise from the clinician and patient which when considered together could be used to create mutually agreed goals. This model which was much more closely aligned with the sociological models of Katon and Kleinman (1981) and Tuckett et al (1985). Medical professionals' autonomy has been acknowledged for over 40 years (Freidson 1988), however the idea of the patient as an equal in the professional – patient consultation has existed within sociological literature from around the same time (Katon and Kleinman 1981; Tuckett et al 1985). Each of these theories consider the role that the professional and the

patient play within the medical consultation with varying importance placed on each participant within the different theories. Tuckett et al (1985) considered the consultation as a 'meeting between experts' with the health professional as expert in their clinical field, and the patient as an expert in their own life with specific insight into their own health condition. Katon and Kleinman (1981) reviewed a number of social science approaches that they felt could be practically applied by doctors. Their hope was to contribute to the development of an approach to patient care which combined social science psychiatric and biomedical frameworks. Their findings indicated the following:

"We feel that negotiation should be an integral part of the primary care physician's work, a core clinical task"

(Katon and Kleinman 1981, p276)

However, despite the longstanding academic acknowledgement concerning the role of the patient in their healthcare, the acknowledgement of this in policy and everyday practice has been more recent. It was this working group that postulated that clinicians should aim to work in concordance with their patients and they defined concordance as follows:

"Concordance is based on the notion that the work of the prescriber and patient in the consultation is a negotiation between equals and the aim is therefore a therapeutic alliance between them. This alliance, may, in the end, include an agreement to differ. Its strength lies in a new assumption of respect for the patient's agenda and the creation of openness in the relationship, so that both doctor and patient together can proceed on the basis of reality and not of misunderstanding, distrust and concealment"

(Blenkinsopp et al 1997, p8)

Concordance is seen as congruent with other methods of patient involvement in healthcare such as shared clinical decision making and patient centeredness.

5.5.2 Policy background of patient involvement in healthcare

The 1990's into the 2000's saw the emphasis of healthcare policy move away from the long standing paternalistic model of care in the clinical encounter towards a realisation of the

importance of the involvement of the patient in the consultation. In 1978 the report from the WHO's International Conference on Primary Health Care stated that:

"All persons have the right and duty to participate individually and collectively in the planning and implementation of their health care."

(World Health Organisation 1978, p17)

While this statement was made in the declaration of Alma-Ata in 1978 it took another 20 years for a start to be made in implementing this in terms of modern healthcare policy. A definitive shift was made towards involving patients in their healthcare decisions in 1998 with the Salzburg Global Seminar's vision of moving towards a partnership between patients and professionals to work in partnership throughout the healthcare journey (de Silva 2012). Since then successive Governments have been supporting increased ideas of patient involvement in healthcare, with the Health and Social Care Act of 2012 providing legislative backing by placing duties on the NHS to promote patients involvement in treatment decision making (Health and Social Care Act 2012).

One of the highlighted difficulties in implementing patient involvement is that there is the lack a definition of what 'patient involvement' in healthcare is (Elwyn et al 2000). It has been commonly conceptualised by as 'patient centeredness'; a term which in itself is ill defined and found to be difficult to assess with current outcome measures (Mead and Bower 2002). Thompson (2007) discussed the interaction between the terms 'involvement' and 'participation' with regards to patients and their healthcare, including the definition of these terms by Cahill (1996). In Cahill's definition, patient involvement is described as the precursor to participation. Thompson (2007) offered a taxonomy of patient involvement and participation in healthcare consultations. This taxonomy was created through a three phase qualitative study design using interviews, focus groups and workshops, with a portion of the participants being involved in all three stages of the project. In each phase the respondents were asked to consider their desired type of involvement in decision making at a health service delivery level. The taxonomy describes a scale of patient desired involvement ranging from 0, non-involvement to 4, patient autonomous decision making. What was key was that patients indicated the desire for different levels of involvement characterised in three types of situations: the type of illness; the patients personal characteristics; and the relationship between the patient and the professional, characterised by trust. This is a

taxonomy which has been created from the patients' perspective of desired involvement. The following definition of patient participation is offered by Brearley (1990) cited by Henderson (2002, p521); "Being allowed to become involved in a decision-making process or in the delivery or evaluation of a service, or even simply being consulted on an issue of care such as activities of daily living, pain management or treatment options." This could perhaps be considered a very broad stroke definition of patient involvement. Certainly, the three main categories of models for patient involvement in healthcare, models of patient centred care, concordance and shared decision making, propose much tighter boundaries on this concept. These three models will be briefly explored in turn.

5.5.2.1 Patient centred care

Patient centred care (PCC) has been the focus of a number of programmes of research as well as policy with the aim of finding and proposing a framework for patients to be explicitly at the centre of their own healthcare. Kitson et al (2013) carried out a narrative review and synthesis with the aim of identifying the core elements of patient centred care within health policy, medical and nursing literature. The majority of the papers that were identified for inclusion in their review originated from nursing literature, the least arose from health policy. Despite not finding common definitions of patient centred care across the literature they were able to identify three core themes that were present across the included literature; patient participation and involvement, the relationship between the healthcare professional and the patient and the context of healthcare delivery (Kitson et al 2013). One of the limitations of this review is a widespread issue when considering the idea of what patient centred care is, namely that definitions tend to be profession specific. The decision of the authors of this review to exclude literature which was outwith the medical, nursing and health policy literature meant that there was no representation of literature from other allied health care professions in relation to their identified core elements of patient centred care. The work of Gerteis (1993) which was included in the above review took a less medical approach in defining patient centred care. Gerteis (1993) considered and incorporated the patient perspective in its broad definition of patient centred care which went beyond issues of communication to include the following dimensions:

1. Respect for a patient's values
2. Preferences and expressed needs
3. Access to care

4. Emotional support
5. Information and education
6. Coordination of care
7. Physical comfort
8. Involvement of friends and families
9. Continuity and transition

These dimensions included both individual and system level issues, however, this work focussed on the acute setting, again failing to consider the more long term aspects of patient centred care required in a rehabilitation setting such as prosthetics. One Canadian study aimed to use a client centred approach to understand the aspects of client centred rehabilitation that were considered to be important from the perspective of clients with long-term physical disability (Cott 2004). The main themes identified during analysis reflected some of the findings of Gerteis (1993), identifying themes that were both specific to the individual in nature and some relating to more organisational issues: individualisation; participation in goal setting and decision-making; client-centred education; preparation for life in the real world; the need for emotional support; feeling isolated and abandoned; and the need for on-going support after discharge. The findings of Cott (2004) reflect the importance to patients of the context of healthcare setting, also found in the review by Kitson et al (2013). There are also commonalities around the aspects of patient centred care which are seen to be organisational and those which are associated with the individual patient and their interaction with the healthcare professional. Kitson et al (2013) recommended that further primary research was needed in interdisciplinary settings in order to move from the single profession approach as different members of the team will focus on different aspects of patient centred care. Their final conclusion was that policy makers needed to look beyond stating the need for patient centred care and towards creating a common language and concepts to make patient centred care relevant to all members of the interdisciplinary team. Entwistle and Watt (2013) proposed the idea of stepping away from the idea defining patient centred care but to reconceptualise these thoughts to a broader ethical idea of treating patients as persons. In this paper they explored this using patients person-al capabilities as the basis for negotiating the relationship between the patient and their healthcare provider. There is still some way to go in understanding exactly what patient centred care means in all areas of healthcare and how it can be implemented in a way which is both equally meaningful to healthcare professionals and patients.

5.5.2.2 *Concordance*

Concordance as defined in section 5.5.1 is based on the notion that patients and healthcare professionals need to work together towards agreement on treatment choice (Stevenson and Scambler 2005). Whilst not an empirical piece of research, Stevenson and Scambler (2005) draw attention to societal changes that are perceived to have affected the patient professional relationship. They offer an explanation for the shift from adherence and compliance models of assessing medical uptake to those that are more focussed on the patient professional relationship in terms of concordance, using a theoretical framework loosely based on the work of (Habermas 1984). Concordance considers the importance of trust in the clinical consultation setting and the mechanisms by which this trust can be violated. However, the evident reduction of trust that can be seen alongside the push for patient involvement has caused several authors to pose a note of caution around the viability of concordance in today's clinical encounters (Greener 2003; Stevenson and Scambler 2005). Further authors have identified that association of trust with high quality interaction and communication and that the professional patient relationship can have a therapeutic effect (Mechanic 1996; Perry et al 1999).

5.5.2.3 *Shared Decision Making*

The concept of shared decision making (SDM) first appeared during the period in which paternalism was the norm within the clinical encounter, with doctors leading the treatment choices for their patients. The work of Maple (1977), a social worker, defined shared decision making as a process including a structured meeting between one person in the role of helper supporting the other person in their role as help seeker to identify goals and a path and plan to reach those goals. When this term was first used there was general understanding around its definition. However, as discussion increased around SDM, the clarity around the definition of the term decreased and interest was shifted to focus on the process of SDM. As a result, models of SDM were developed which were designed to assist in the incorporation of SDM into the healthcare environment (Charles et al 1997; Charavel et al 2001). Charles et al (1997) identified four characteristics considered to be the minimum required to achieve shared decision making:

1. The decision making process must include a minimum of two people, of which one is the clinician and one the patient
2. Each of those involved in the decision making process must take steps to participate in treatment decision making

3. For shared decision making to be achieved there must be information sharing between those involved
4. A decision must be made on a treatment which each of those involved in the decision making process agree on

Montori et al (2006) discussed this model of shared decision making in relation to chronic conditions vs. the acute care setting. They identified that it was likely that the decisions made in the acute care setting were often life-changing, irreversible and urgent whereas with chronic conditions were more likely to require a more active patient role, that there would be a longer time period for these decisions to be made and the opportunity for them to be revisited or changed without serious lasting outcomes. For these reasons, Montori et al (2006) considered that the process of shared decision making should be setting specific. The model proposed by Charles et al (1997) was developed to define SDM in the acute care setting where decisions involve discrete treatment decisions for serious acute care illnesses that will have important and immediate effects for the patient. Montori et al (2006) propose that within chronic care, the model of SDM proposed by Charles et al (1997) can also be applied but with some alterations and recommendations. The first, and the one which they place the most emphasis on, is that of the development of a partnership between the patient and the clinician and the importance of spending time on this step in the process. The focus on this aspect is designed to foster trust and enhanced communication between the clinician and the patient and the benefits that this can yield in the rest of the SDM process. They also consider where decisions and information exchange is occurring for patients in a chronic illness situation; that they occur not only in the healthcare space but in the patients' space outwith that healthcare setting.

Shared decision making has been criticised as being a theoretical model which cannot be implemented in its theoretical form to decisions made in day to day decisions in healthcare. Gafni et al (1998) discussed this ideal shared decision making by first discussing the models of treatment decision making which shared decision sits between. On one side is 'the physician as perfect agent model' and on the other 'the informed decision making model'. In order for the physician to act as 'perfect agent' they must understand all of the patient's values, preferences and opinions, as well as their goals, and combine all of these things with appropriate clinical knowledge. Similarly, in order for a patient to be fully informed in making a treatment decision they must have sufficient clinical knowledge and be able to combine that with their own preferences, goals and values. The implication being that both of these models are aspirational, that no individuals have the same experience and they

must work together and contribute their 'partial' knowledge to come to a decision. Gafni et al (1998) concluded that there was a need for models of decision making which more closely reflected what was happening in decision making in clinical practice and proposed that it would sit somewhere on a spectrum between the two models discussed.

Each of the models discussed above work on the premise that patients want to be involved in the process of decision making about their treatment. Guadagnoli and Ward (1998) carried out a review of patients' desire for participation in healthcare decision making; they found that patients want to be informed about treatment alternatives and that in situations where there is more than one effective treatment they want to be involved in the treatment decision. There is a growing body of literature which indicates that patients' seek different roles in healthcare decision making as well as varying levels of participation (Ende et al 1989; Guadagnoli and Ward 1998; Chewning et al 2012; Slover et al 2012). Chewning et al (2012) carried out a review of patients' preference for shared decisions, covering literature from 1980-2007. They found that in 63% of the included studies, patients preferred shared decision making. This increased to 71% when looking at studies published from 2000-2007 compared to 50% in studies from before 2000. They also reported that patient population influenced patients' desire for participation, with a greater preference for participation among studies in cancer populations (77%) compared with general populations (53%), and reducing to 46% for patients with chronic conditions. In their implications for practice they highlighted the importance of noting that the nature of the decision, as well as the stage of the patient-provider relationship, could have an effect on the patients' desire for participation. The idea that 'relationship' plays a role in patient preference is seen in the work of Thorne and Robinson (1989) on on-going health care relationships. They found that at some points in the relationship, factors such as trust in their healthcare professional, will lead to variations over time in their desire to participate in decisions.

Despite the policy drivers and research around inclusion of patients in their healthcare decisions, barriers can be seen to exist to incorporating this approach into day to day healthcare delivery. An updated systematic review of the barriers and facilitators to implementing shared decision making in clinical practice was undertaken by Légaré et al (2008). They used the following definition for shared decision making:

“a joint process between health professionals and patients for making health related decisions, or as decision support interventions such as decision aids, or as the active participation of patients in decision making”

(Légaré et al 2008, p527)

They found that despite the growth in the field of shared decision making research in health there was a lack of knowledge around the effective implementation of shared decision making in clinical practice also found in other research (Duncan et al 2010). For future practice they identified the need for further research into the time involved in incorporating shared decision making into clinical practice in comparison to normal care. They also highlighted that clinicians could gain by simply asking their patients about the role they would prefer to play in decision making about their health. This review shows that the incorporation of patients in their healthcare decisions is still not routine and that more work is required to incorporate shared decision making into day to day healthcare situations.

Prosthetic rehabilitation and review is a long term process, one which gives an opportunity for a relationship to develop between the patient and those involved in their rehabilitation. This differs from the decision making environment in the primary care where interaction are often regarding a specific ailment. In prosthetic rehabilitation environment it would seem possible that patients should be able to contribute to decisions relating to their care despite their limited technical knowledge. Thinking about the existing knowledge that I have of prosthetic care it would seem possible at the very least for prosthetists to have the opportunity to discuss with their patients the role that they would like to play in clinical interactions about their prosthetic care. Due to the longitudinal nature of the prosthetic rehabilitation process it also seems possible that this is something that could be reviewed over time in order to allow patients to amend their level of involvement as their personal situation evolves and changes over time.

6 Chapter 6 - Clinical Judgements and Decision Making in Prosthetic Prescription

6.1 Introduction

The results of Study 1 are based upon the findings from a sample of nineteen participants involved in the delivery of prosthetic rehabilitation to trauma related amputees. These included two service managers, eleven prosthetists, three rehabilitation consultants and three physiotherapists. This chapter presents findings which address question 2 of study 1 as follows:

2. What factors (clinical and non-clinical) are used in the judgements and decision making of prosthetists during prosthetic prescription for civilian trauma amputees and service attributable amputees?

The focus of the chapter is primarily on the role of prosthetists and how they make judgments and decisions when forming a prosthetic prescription. It will also explore the involvement of a number of other health care professionals who are involved in prosthetic rehabilitation.

Initial findings from the scoping study indicated that prosthetists and rehabilitation consultants were the main healthcare professionals involved in prosthetic prescription which led to the sample originally chosen for the study. While a range of different clinical groups, prosthetists, rehabilitation consultants and physiotherapists participated in the scoping study, the findings from the scoping study did not elicit the importance of physiotherapists in the prescription process. For this reason physiotherapists were not originally identified as a target cohort for study 1. However, during initial interviews with prosthetists in study 1 it became clear that they considered the involvement of physiotherapists to be important during the prescription process. A group of physiotherapists was therefore included to compliment the data gathered from the prosthetists and rehabilitation consultants, and to better understand the role which physiotherapists play in the prescription process from their perspective. This chapter explores the roles that these different clinical groups have in prosthetic prescription, highlighting where they agree and disagree on their level of their involvement.

6.1.1 Decision Making in the Clinical Setting

Seven main themes emerged from the data; the first two related to prosthetists' assessment of, and their interaction with the patient, these were 'Here and now' and 'What they were and could be again'. 'Here and now' comprised the information which prosthetists gathered from the patient during the assessment considering those aspects which must be addressed as they appeared at that point. 'What they were and could be again' includes the aspects of the patients' life prior to amputation which could evolve over time and which could be incorporated into the prosthetic prescription. The remaining five themes related to the prescription decision and the factors which contributed to that decision. The first decision related theme was 'The active role of the patient' which explored the discussion, negotiation and interaction between the prosthetist and patient during the prescription process. A further theme, 'Prescription challenges', explored external factors which impact on the prosthetic prescription process, for example, financial constraints. The remaining three themes included practices which the prosthetist may engage in order to supplement the information they had gathered during the patient assessment process, 'Peer decision making and discussion', 'Multidisciplinary team decision making' and 'Tacit, experiential and technical knowledge'. Once the themes had been identified and descriptions of the contents of those themes defined it was possible to relate these to the judgment or the decision. The organisation of the themes relating to each of these broad aspects of the decision making process is illustrated in Figure 17. This is also the data analysis matrix which was used to code all data relating to the second research question.

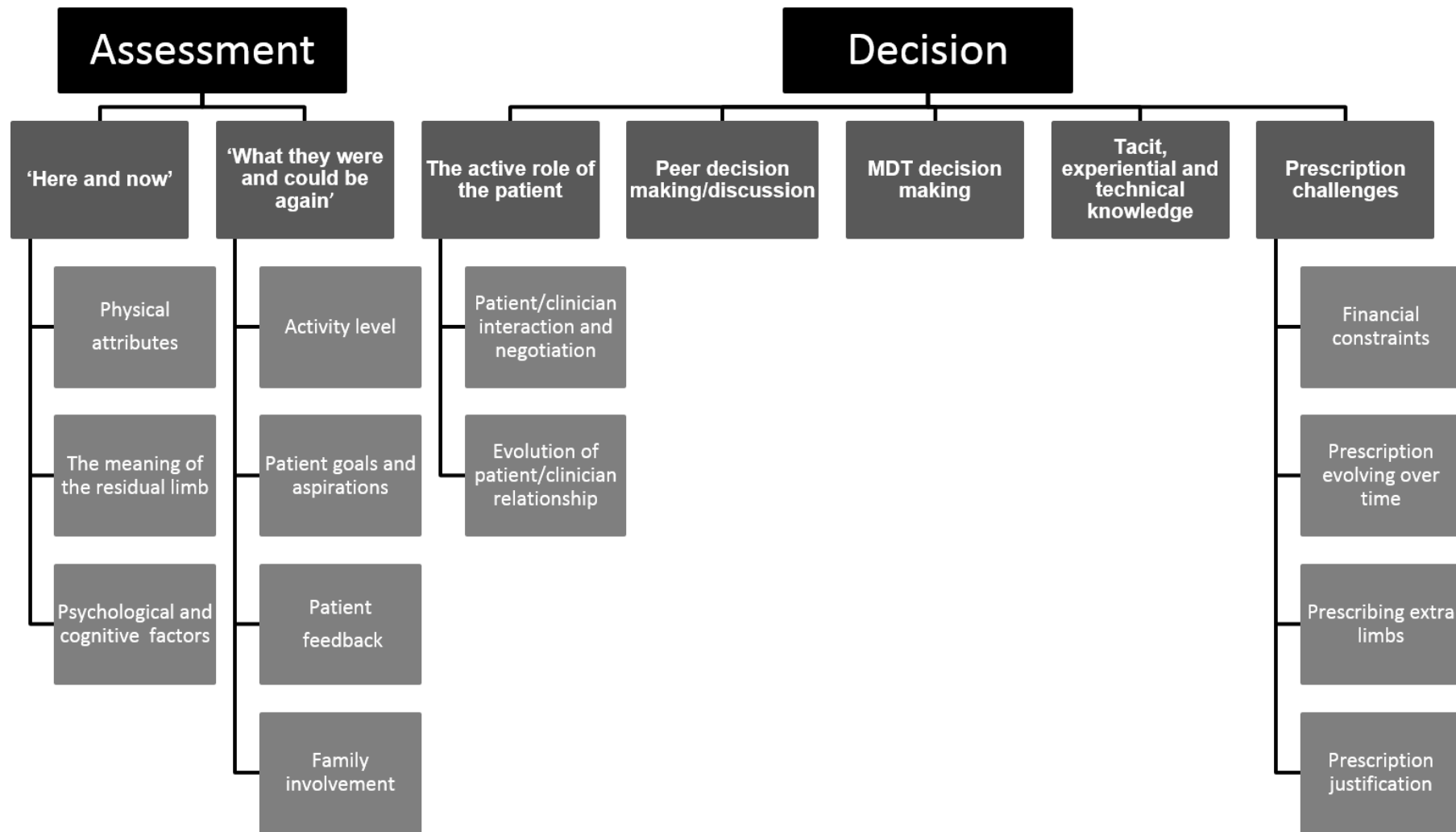


Figure 17: Data analysis matrix: Clinician Decision Making in Prosthetic Prescription

6.2 Assessment (Judgement)

The two main themes, 'Here and Now' and 'What they were and could be again' and their sub-themes encapsulate all of the factors presented by the patient during their assessment appointment, including physical factors that prosthetists are trained to assess and factors which the patients highlight in response to questioning during the prosthetic appointment.

6.2.1 'Here and Now'

When a patient meets the prosthetist for their first assessment there are aspects of their presentation which cannot easily be altered and therefore need to be considered as they are at that point for the purpose of prosthetic prescribing. 'Here and Now' discussed how each of these fixed factors influence the prosthetic prescription and how critical a role some of these factors played. These include the patient's general physical health and physical attributes, including comorbidities, age, weight and condition of the residuum. Although some of these factors can change throughout the prosthetic rehabilitation process (for example, the condition of the residuum may change) when prescribing, the prosthetist must work with these factors as they are 'here and now' at the time of the patient assessment. These fixed factors are discussed under three sub-themes, 'Physical attributes', 'The meaning of the residual limb' and 'Psychological and cognitive factors'.

6.2.1.1 *Physical Attributes*

Prosthetists described gathering patient information that they described as 'basic information'. This information which was seen as important was routinely gathered but it was not always clear how it was used to inform their judgement and subsequent decision. For example, many prosthetists identified age as being a factor in their assessment but then only gave explicit explanation about why being a young patient would affect the prescription choice. This in general, related to a greater expected activity levels of younger patients compared to the average prosthetic patient population in Scotland who is likely to be older. There was also considered to be a connection between age and the type of injury or disease which had led to amputation and the expected outlook of those patients. However, using age in isolation was not always reliable, as highlighted by two prosthetists.

"...sometimes it's taking their age alone and setting what you think is going to be their care level is sometimes a bit skew because I found to my cost that you could be a 70 year old and do much more than a 40 year old!"

(ST06- Prosthetist)

Conversely, one prosthetist talked specifically about using age as a factor even if the mode of injury was traumatic, thus highlighting the importance of age in prescription choice for this clinician.

“...patient’s age and fitness before the accident or whatever happened to them. That’s a huge influence. I’ve had trauma patients that are older patients, probably think about them the same as any vascular patient, definitely their age is the major factor.”

(ST04- Prosthetist)

Weight was an important factor, both in relation to the weight of the patient and the weight of the prosthetic components, which was discussed in a simpler manner. Prosthetists explained that the weight of the patient could have a direct effect on the number of components available as these are classified by the weight of the patient that they are designed for. As a result the heavier the patient the smaller the choice of available components.

“If you look at the size of a person and/or their activity and their weight and you think ‘we want something strong here’ so that might rule out some of the less reliable parts.”

(ST01- Prosthetist)

Conversely when prescribing for a patient who is light, prosthetists highlighted that the weight of the components being prescribed must also be considered. In these cases prosthetists reported that they would try and keep the artificial limb as light as possible.

“He was quite a lightweight guy as well so we were trying to keep everything as light as possible in what we could prescribe. I looked at two different feet and I narrowed it down to two different feet, or three actually, and we ended up with the lighter of the higher activity ones which he was prescribed in the end.”

(ST07- Prosthetist)

The weight of prescribed components was also considered from the perspective of maintaining the suspension of the prosthetic limb. One prosthetist talked about a case where they were prescribing a prostheses for a patient with a short transfemoral stump and what the consequences of that were for prosthetic prescription³. Their choice of components was influenced by the need for the combined weight of all components to be kept as low as possible in order to assist in maintaining suspension of the limb.

6.2.1.2 *The meaning of the residual limb*

Prosthetists identified a number of issues about the residuum which they considered during the assessment, including any allergies the patient had, the length and shape of the stump and the presence of any skin grafting or significant scarring. Of these, there were two factors which were dominant; stump length and the presence of scarring and skin grafts. Prosthetists' perspectives on the impact of these factors on the prescription were discussed in more detail. Firstly stump length, both in cases where it was considered too long or too short, was seen as playing a key role. Prosthetists talked about situations where having a long stump reduced the space available for components below the socket and cases where if the stump was short it could cause difficulties with the suspension of the prosthesis. In each of these cases there was a reduction in the number of suitable components which could be used.

"...and I know I've said stump length already but it's really important what will fit in the available space in conjunction with the socket design; so if you're going to use something like a pin, do we have room for that and some other kind of knee or..."

(ST01- Prosthetist)

The presence of scar tissue and skin grafting was also raised several times. Prosthetists indicated that these types of tissue are not as inherently tolerant to the external forces exerted on the stump by the socket during prosthetic ambulation as normal skin tissue. These external forces, which are normal and unavoidable, can cause breakdown of fragile scar and grafted

³ In cases where the residuum is short, suspension is harder to achieve, in these situations keeping the weight of the prosthetic limb to a minimum will increase the likelihood of achieving adequate suspension of the prosthetic limb on the residuum

tissue. The presence of this type of tissue on the stump requires a prescription which will reduce the effect of these external forces resulting in a reduction in the choice of socket prescriptions available. It was identified that trauma amputees were more likely to have a stump with excess scarring and skin grafting in comparison to vascular patients. This could have direct consequences for socket design.

“The fit of the socket for ages was an issue cause we tried... she had a lot of skin grafting, so it was trying to decide on what liner to use and should we go for custom liners, should we not go... and that was all dictated by just her leg, it wasn’t my opinion at the end of the day we just had to work around it.”

(ST04- Prosthetist)

Liners were also seen to be indicated to prosthetists in cases of Heterotopic Ossification (HO)⁴. Among amputees this condition is seen almost exclusively in veterans. Prosthetists talked about the effect of HO for an amputee being that the condition of the stump was not static. A patient with HO could present with a pain free stump one week but with the growth of bony shards associated with HO, the fit and comfort of their prosthesis could be altered the next. The presence of HO could therefore affect the socket prescription.

“...but I suppose it probably wouldn’t affect what I was giving them particularly unless they’ve got this HO heterotopic ossification and things then you might be considering giving them silicon liners and that right from the word go...”

(ST05- Prosthetist)

The prosthetists referred to these factors in different ways, either as narrowing their choice of prosthetic components or providing a clear indicator of what should be prescribed. For example, they reported the presence of scarring having a profound effect on socket design, i.e. liner etc. and length of stump (short or long) narrowing their choice of components.

⁴ Heterotopic ossification is a condition in which shards of bone begin to grow within soft tissue such as muscle and skin. This condition was previously uncommon in amputees but in recent conflicts it has been seen to be a common clinical problem in trauma patients(Potter et al 2010)

6.2.1.3 Psychological and cognitive factors

This sub-theme reflected how cognitive factors can impact on the prosthetic assessment and prescription choice and how the patients' psychological status can impact on their interaction with prosthetic rehabilitation and what they ultimately may be able to achieve from it.

One prosthetist discussed the difficulties of having a patient who had had a head injury and resulting memory difficulties and explained the limitations this can bring to providing them with a prosthetic limb as well as some ways of overcoming those issues.

"Sometimes you need to actually have photos with explanations. If, say, they have a poor memory they can look at the pictures and follow it step by step or, the care worker will come with them and we'll show them how to do it.... I'd still look at what the limb was going to be used for. And how tricky it might be to don, like you know, would they manage an Iceross liner?"

(ST12- Prosthetist)

Prosthetists described their views on the effect that different modes of amputation have on the patient psychologically and some of the ways that this could impact on the process of prosthetic rehabilitation. Prosthetists considered different psychological consequences of mode of amputation, particularly traumatic. In general they felt that traumatic amputation had a different and perhaps more detrimental psychological effect than vascular amputation. While prosthetists were aware of this psychological trauma it was not described as part of the assessment for the prosthetic decision but appeared to be important in the overall process of caring for those patients.

"I think she's suffering post-traumatic stress because basically she lost her leg in an... it was almost like an IED, she was in a temple and the pressure cooker fell off the kitchen, you know, the pressure cookers tend to rattle when they're hissing and it was an industrial sized pressure cooker, so it fell off, the lid had come off and basically took her leg clean off..."

(ST06- Prosthetist)

"The traumatic guys it's happened to them, they don't really... they knew nothing about it at the time kind of thing and they wake up and there's two sides of that, you've got the ones that deal with it extremely well and go 'okay, I'm an amputee let's get on with it' and you get the other ones that are 'I can't believe this has happened to me, I'm absolutely devastated' and it's very difficult for them to get over that."

(ST05- Prosthetist)

"...but her biggest hindrance was the psychological impact of that and not... which then translated onto the leg because she never really...she wouldn't accept that she'd become an amputee and was always wanting the leg to feel like her leg had been and it was a real struggle for a long time to get her to accept it won't be the same... at the end of the day it was mostly the psychological impact of it, it wasn't actually the leg itself."

(ST04- Prosthetist)

One prosthetist also suggested that vascular and elective amputees showed a certain amount of relief at the point of amputation as patients tend to view the affected body part as 'this thing which is causing them pain', reducing their quality of life and maintaining their illness status.

"Vascular patients...they have usually had quite a long lead up to the point where they've had their leg amputated so in some respects they've been quite prepared for it happening and in some respects they're actually quite glad it's happened because they feel so much better once this horrid infected mess at the end of their leg has got amputated, they feel a lot better afterwards."

(ST05- Prosthetist)

"In very broad terms, they present completely differently because they need more support in different areas. Maybe the whole shock of the event that's happened to them affects their treatment more than the vascular. The vascular patient, often their amputation has caused them a great benefit, you know, the absence of pain,

for example. So they're much more accepting of their condition and they've maybe had time to prepare beforehand."

(ST09- Prosthetist)

One prosthetist talked about how it was impossible to guess how any patient would deal with an amputation irrespective of the mode of amputation. They highlighted that, as above, some traumatic amputees struggled to cope because the limb loss has been sudden and that they had no time to adjust. Conversely some trauma amputees, upon realising they had lost limbs, were very pragmatic, quickly accepted their condition and moved on. This prosthetist also described patients who had undergone an elective amputation who then struggled either because they wish that the amputation had happened years ago or because they wished that the limb could have been saved.

While most of the prosthetists indicated that they felt traumatic amputations were more detrimental psychologically there was some feeling that this was not always the case. The psychological effect of amputation did seem to be something that prosthetists thought should be considered in the management of amputees. They recognised that for some amputees a negative state of mind after amputation could have a lasting effect on their prosthetic rehabilitation if not correctly addressed. They recognised that all patients were different and that it was difficult to gauge what any given patients reaction to amputation would be. This could indicate that closer attention could be paid to the psychological state of all patients post amputation no matter what their mode of amputation.

It could be seen even during the assessment that prosthetists were using the information gained from their assessment of the patients' current condition to synthesise their knowledge of the large number of prosthetic components available to them and to start a process of narrowing down that choice. Some factors from the assessment seemed to carry more weight in this process. For example weight (both component and patient) appeared to be more important than age. The importance of individual factors could be dependent on the prescribing prosthetist or through the combination of factors found during the assessment.

Prosthetists talked about the 'Here and Now' as the assessment of a series of physical and psychological factors which came together to begin the formation of a conceptual prescription.

This conceptual prescription was then further developed when the prosthetist discussed with the patient what they hoped to achieve as an amputee.

Key points:

1. It was felt that mode of amputation could affect patients psychological state post amputation but that this varied from patient to patient.
2. Prosthetists considered some factors to be more important in leading their choice of prosthetic components, for example weight (both the patients and components), age, presence of scarring and length of stump.

6.2.2 'What they were and could be again'

Of course each patient is more than their residual limb and the theme 'What they were and could be again' explored how prosthetists assessed their patients in a more holistic way. It encapsulates factors which prosthetists reported assessing about the patient as a whole and the impact which these had on the prosthetic prescription. It takes into account how they were prior to amputation with regard to activity level, what they were able to achieve at the time of the assessment and what they were predicted to be able to achieve in the future as well as how this prediction was made. This theme also includes the way in which prosthetists assessed patients' goals and aspirations as a prosthetic limb wearer by considering what they were able to do before amputation and what they wanted to be able to achieve in the future. It looked at the role that the clinician had in matching these aspirations with the prosthesis

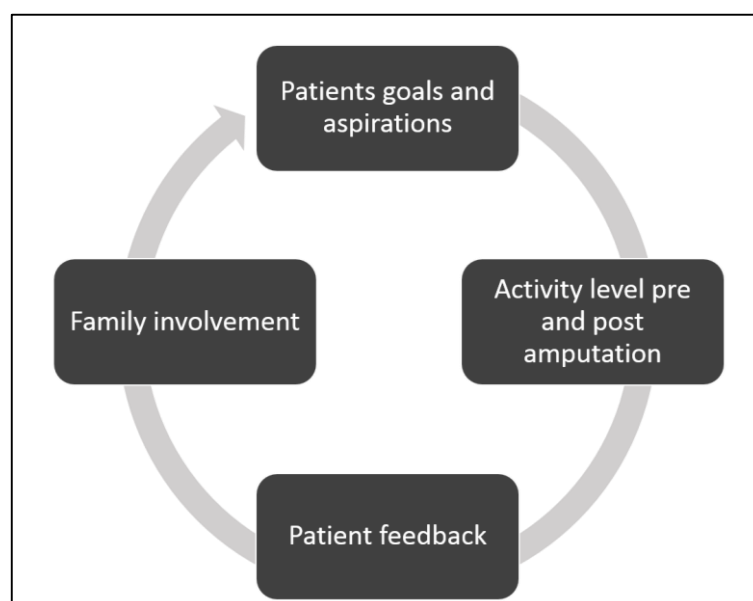


Figure 18: Interaction of the sub-themes in 'What they were and could be again'

they selected and how they influenced the prescription choice. Figure 18 shows how each of these aspects are interlinked and flow on from one another.

6.2.2.1 Activity level

Almost all of the prosthetists identified patient activity level pre and post amputation as an important factor in deciding on the most appropriate prosthetic prescription. Activity level was important firstly, because prosthetic components are graded in relation to the sorts of patient activities that they have been designed and tested to withstand. This judgement required a balance between providing the patient with a prosthesis that they could cope with as a new amputee, and yet that they would not mature beyond too quickly. To do this prosthetists talked about having to predict or make an 'educated guess' on what they thought a patient's future level of activity might be. They talked about this prediction being made based on a number of factors including the reported level of activity of the amputee prior to amputation, feedback from physiotherapists on what they achieved pre-prosthetically, what their fitness levels and general physical health were and the presence of any comorbidity.

"We would use the K levels, they [physiotherapists] put in their assessment form they have... I don't know what one it is, but it's like... how many steps they take and how many aids they use, and then they do a predictive one as well which comes through whenever you get a primary through."

(ST07- Prosthetist)

"It's, kind of, a group decision between the patient, the physio and myself...I will have been introduced to my patients before they're referred officially to me so I've met them and observed them having some of their pre prosthetic physio, using the PAM aid or the early walking aids. The physio and the patient will have had lots of talks about how they're doing and what their previous mobility was and what their expected mobility will be, before they come to see me for their first proper primary assessment."

(ST09- Prosthetist)

What they discussed as being an important factor in this prediction was the mode of amputation. Clinicians argued that this aspect had a large effect on a patient's general fitness and wellbeing. Prosthetists reported being more confident in forecasting the activity level of

trauma amputees. From the perspective of the prosthetist this was an easier prediction for a number of reasons; trauma patients were less likely to have multiple comorbidities which would affect their future activity levels; the trauma had generally happened when they were young and at their physical peak prior to injury, therefore they reported feeling safer in the assumption that they would reach their pre-amputation activity levels. Due to the suddenness of trauma amputation these patients had not had time to become de-conditioned and were less likely to have any comorbidity.

“And both these young guys I’m talking about were young and fit with no other physical problems...And that was a big factor in the final prescription that we ended up giving them was that, you know, these guys were obviously going to go back to work and go back to college as it was...”

(ST05- Prosthetist)

“...he was already a fit guy that did participate in a lot of sports as well and obviously just the route he’s came through, there was no underlying medical problems; he was a fit, healthy guy that just had his leg off. So yeah, that was the driving force and then obviously taking everything else into account...Vascular patients and trauma patients are really very different in that the vascular patients they’ve got usually loads of other co-morbidities so they probably aren’t terribly well generally, their life expectancy is not as good, they’re less likely to do well.”

(ST06- Prosthetist)

“...so the people who bizarrely have an accident and lose their limb straight away can sometimes be easier to rehabilitate because their general health is still good and their general mobility is still good, they haven’t had any time to become de-conditioned, so they’re very fit and healthy, something dreadful’s happened, we fix them up and get them hopefully back to, you know, as near normal as possible.”

(ST10- Prosthetist)

This was discussed as being the case for amputees who had been healthy and suffered a trauma and amputation either at the time of injury or shortly after. However, in some trauma cases patients may have undergone a lengthy period of reconstructive surgery in order to try

and save the limb. Prosthetists reported that this could lead to de-conditioning of the patient, a reduction in their general health status and subsequently a reduction in their expected activity levels post amputation. A similar reduction could be seen in trauma cases where patients had suffered other injuries as a result of their trauma, such as damage to the contralateral limb which could impact their prosthetic rehabilitation. In these cases prosthetists reported more difficulties in predicting their future level of activity.

“If somebody’s had a bad injury, say a crush injury or a non-healing fracture and they’ve had many operations over maybe a couple of years, you know, and had X fixes in and they’ve been limited in their mobility, that can sometimes be harder to get them back to their physical peak.”

(ST10- Prosthetist)

In cases where the patient had gone through a long period of de-conditioning⁵ as a result of disease which ultimately led to amputation, prosthetists reported that it was harder to gauge what level of activity they would get back to, indeed, some of the patients in this category were not even put forward for prosthetic rehabilitation.

“...as opposed to people with other health issues who’s activity may have been diminishing as time has gone on as they start to feel the effects of their illness, you know, and so then it can be hard to gauge what the true activity level standard might be.”

(ST01- Prosthetist)

“A lot of the vascular people they’ve been so ill with this bad leg that they’re really de-conditioned, but actually once they have an amputation some of them surprise you and do really well, but not all. So there is definitely a difference with how we predict what the vascular traumatic, the non-vascular traumatic amputees will be.”

(ST10- Prosthetist)

⁵ The decline of the patients’ general health associated with a period of disease or immobility

Prosthetists also had to consider that in the vascular amputee population there was a higher likelihood of comorbidities such as heart disease and arthritis which affected these patients' ability to use a prosthetic limb. Walking with a prosthetic limb greatly increases the users' energy expenditure (see section 2.1.1.1) thus increasing the required effort of the heart. The presence of arthritis can affect the joints proximal to the stump as well as the contralateral limb decreasing the joint range of motion required for limb fitting and ambulation. These factors were noted to affect the amputees predicted activity level therefore impacting on the range of prosthetic components that the prosthetist were able to provide.

"...and then they'll be their physical capabilities so do they have issues co-morbidities, so do they have arthritis, vascular disease, you know, so you look at range and motion at their joints, strength of their joints, any other conditions they might have that would affect them. So that's one thing..."

(ST10- Prosthetist)

When considering what the patients' expected level of activity prosthetists reported that they anticipated that the prescription they provided for a primary patient would need to be revised at some point. The prosthetists indicated that the requirements for a primary prosthetic prescription were two fold. Firstly the patient needed to be able to comfortably learn to walk with it and secondly that it would meet their activity needs over approximately the first 6 months to two years following amputation. Prosthetists were not just thinking about the immediate activity requirements of the limb but also ensuring that it could withstand the patients' projected activity level of around six months to a year from the initial prescription.

"...similarly what you might find is if you look at somebody in front of you and you give them something that's appropriate to that time then they do change, they get better, you know, their health improves, they become more active and then you relook at things. So I suppose everybody's individual but, yeah, they have to manage what you give them now but with a nod to what they can achieve in the near-ish future, I think six to twelve months would be the sort of timescale we'd be thinking about, not in five years!"

(ST10- Prosthetist)

“With a traumatic amputee the likelihood is that as their stump matures and their pain levels reduce and everything else and if they've got no other physical problems, their activity level is likely to go back up to the level it was before. I'm quite a firm believer in providing somebody with a leg that is easy for them to learn on and then once they've learnt to do whatever they want to do on that, primarily to walk on it, if they come back and say ‘actually I'm doing a bit of running’ then you can probably upgrade their prescription at that point and then you then have a spare leg for them.”

(ST05- Prosthetist)

Prosthetists admitted that their predictions of a patient's future activity levels were not always right and had to be reassessed. However, as described in section 6.3.5.2 the need to change the prescription was anticipated highlighting that the prosthetic prescription is not expected to be a one off decision. The primary prescription is not intended to last indefinitely and while it was considered beneficial not to have to change the prosthesis too often if it was clinically indicated that it could be changed.

Key points:

1. Prosthetists found it easier to predict the future activity level of trauma patients without associated injuries than that of trauma patients with associated injuries and patients with amputations resulting from long term disease.
2. The ability to predict a patient's future activity level helped prosthetists to identify prosthetic components that would be appropriate for their patients over their initial prosthetic rehabilitation.

6.2.2.2 Patient goals and aspirations

This sub-theme is closely related to the patients' level of previous and predicted activity but goes beyond that to explore prosthetists assessment of what their patients hoped to be able to achieve. While prosthetists identified a large range of factors which affected their prosthetic prescription they were vocal about their patients' goals, aspirations and personal preferences as being one of the most important factors.

“I think perhaps aspirations is the big one...”

(ST01- Prosthetist)

“...and the most important thing on that sheet that we ask them is their aspirations as well.”

(ST06- Prosthetist)

Prosthetists talked about patients' aspirations and goals as covering a wide spectrum, while they reported that they had some patients whose expectations were high and they aimed to achieve something which could be considered out of the ordinary even without an amputation, they also reported that patients were commonly looking to get back to their everyday lives. One prosthetist talked about their patients' goal being able to kneel in their prosthesis to pray, another spoke about a patient who lived in a hilly area and for others it was about getting back to work and the benefits which this had for the patients well-being and self-efficacy. Each of these aspirations had a direct effect on what the prosthetist then prescribed for that patient and even in some cases this meant compromising on other areas of the prosthetic prescription.

“The other guy had a young family, wanted to get back to work, doing the same job that he was doing, yeah, I mean we'll gladly help people get back to work, at the end of the day if they're back at work they're paying their way in life and that's great, that's probably quite a high factor is trying to get them back to work as soon as they can because it improves their sense of wellbeing and everything else as much as anything else, they start to feel better about themselves 'look at me I'm back at work!' and things aren't quite as bad...he needed a multi-axial foot that would allow him to do that comfortably, it could've resulted in him having more stump problems if we hadn't given a foot that would comply with the ground that he was walking on, quite so well, that's why we ended up... I think his final prescription was a College Park Trustep foot he got which is very compliant and allowed him to walk over the ground that he needed to.”

(ST05- Prosthetist)

“...she wanted to be able to take her shoe off easily and kneel in the temple...she couldn't really kneel with the sleeve on so I compromised and went to a shuttle system which I don't think's ideal for her limb, but she can flex her knee easier...”

(ST06- Prosthetist)

This showed that prosthetists aimed to listen to patients' goals, aspirations and preferences and to use that information to inform the prosthetic prescription. Different prosthetists varied in how they described this in the interviews but it was clear that they wanted to take the aspirations and goals of the patient and where possible balance them with their physical needs to create the most beneficial prosthetic prescription for their patients. Patient preference was considered in relation to the prosthetist's clinical knowledge, in this way if the patient was asking for something which they deemed to be clinically inappropriate then they would not provide it.

"Cost [laugh] so certain items would be outwith our budget, but generally... so we're talking about the high end type components, but really excluding that, no, you know, we try and match the patients' aspirations with their physical need as best as possible."

(ST06- Prosthetist)

Prosthetists also talked about prioritising their patients' needs as in some cases it was not possible to achieve everything which the patient wanted in one prosthetic limb. This could also be seen to tie in with managing the patients' expectations of what they would be able to do with the limb they were prescribed.

"...that's hopefully where our clinical skills come in that you do decipher okay... and I would even say 'so what's the most important thing out of all of that?' you know, 'how are we going to prioritise these needs?' cause it might not be that one item can tick all these boxes,"

(ST01- Prosthetist)

Prosthetists spoke about having to decide if the patients' goals and aspirations were realistic or not. They reported that in cases where the initial expectation appeared to be unrealistic that they had further discussions with the patient about what they were able to do prior to

amputation and used this information to gauge how realistic it was. For example a number of prosthetists used an example of a patient saying that they wanted to run a marathon but after further questioning it became clear that they had never run before, in these cases they discussed having considered if that patient would ever be fit enough to attain that goal. However, one prosthetist related a case where the patient had attended with a goal which seemed to be unrealistic especially on considering their weight and fitness level, despite this the prosthetist prescribed them a limb which would enable them to achieve what they wanted and subsequently they proved to them that they could achieve that goal.

“The prescription difficulty I had is what they said, what their goals were and what they said they were doing prior to their accident, the clinical findings didn’t back that up. They were quite...their BMI was really high, their exercise tolerance was quite poor, but they claimed they wanted to be really quite high functioning...We decided to go for something that would give her a good functional outcome, despite her high BMI. We decided just to go for, you know, what she said she wanted to do.”

(ST09- Prosthetist)

Patient expectations were also reported to evolve as they became more established amputees and could see more clearly what they would like to or might be able to achieve with a prosthetic limb.

“So I’ve got a guy now that never played golf before, he was a builder, he used to ride motorbikes, that was his hobby, suddenly had an accident, forbidden to ride motorbikes by his wife, he had to find another hobby and he took up golf and the requirements from the limb that I made him at the start to what he subsequently led onto was driven by him changing direction. So he now plays golf at a very high level in the sort of disabled field and he’s gotten a limb now that’s very specific both for playing golf and he was a site manager in a building firm, so the limb... and at the start he was never going to go back to that, you know, he thought he couldn’t do it because it was walking on the building site and he knew he couldn’t manage it, and then all of a sudden he found out he could so the limb that he got at the start he was just wearing out...”

Conflicting views were expressed about when it was important to talk to patients about their goals and aspirations; some expressed the view that it was something that should be discussed right from the initial assessment appointment whereas others felt that it was not required until later in the rehabilitation process. The argument from those that felt it was important to get this information early was that it could indicate that they needed to manage their patients expectations and also so that they had an early indication of what the patient hoped to achieve in the future even if they could not at that early stage. Conversely other prosthetists indicated that it was important in the first instance to prescribe a limb that would allow the patient to get up and walking and subsequently consider if their patient would like to or could do more with their limb. In either case considering patients aspirations was an ongoing factor in prosthetic prescription and combined with patient feedback effected changes in prosthetic prescription to allow the functionality the patient wanted or needed.

6.2.2.3 Patient Feedback

When discussing activity level of primary and established amputees, prosthetists talked about the different impacts that this had on the prosthetic prescription. With primary patients the level of activity that the patient needed their prosthesis to withstand was predictive whereas established patients' prosthetists relied on feedback from the patient. Feedback could be used by the prosthetist to assess if the prescription provided was still appropriate or if it required revision. Prosthetists were then able to take the patients' feedback to inform possible changes in the prosthetic prescription in order to more closely match it to the patients' needs and wants. They discussed that the feedback which patients provided throughout their prosthetic rehabilitation was invaluable for prosthetic prescription. In addition the longer the patient had been an amputee the more experience they had of different prosthetic components. This also helped guide the prosthetist in their subsequent prescriptions. The importance of this feedback is highlighted when one prosthetist spoke about a patient who found it difficult to articulate their experiences as a prosthetic limb wearer.

"...sometimes people genuinely find it very hard to explain what they're feeling. Articulate people but they find it really hard to translate what they feel down there into words because it's new I guess sometimes, and mind you I can think of an established amputee who laughs at himself, he just can't put into words what he's

feeling and that can be really difficult. So I guess if the individual's got communication difficulties, it's a lot more of a struggle, but I suppose that just goes to show how big their role is..."

(ST01- Prosthetist)

Prosthetists sometimes discussed the prescription of a prosthetic limb as a process of trial and error, this could be through a protracted process of providing a new components and reviewing after a period of time. Alternatively prosthetists had the option of getting trial components from the manufacturers and trying them out for a short period. If they found that they were not beneficial for a patient they could be returned free of charge. In both of these situations patient feedback was key in ascertaining the suitability of the prescription for the patient. When using trial components prosthetists reported patient feedback as the most important factor when choosing between the components they had tested.

"You can, we're going to do that for somebody – not this guy but somebody else shortly – some of them will have 60 day trials, so what we'll do is we'll say 'okay, we think these three or four would be suitable for you but you do some specific activities that we don't have a lot of experience in so let's try it and see which is better for that specific thing' and hopefully you can send back the ones you don't use [laugh]! And again that really puts then the decision making to the patient because then they can say 'actually I like that one better than that one'."

(ST10- Prosthetist)

"Yeah, yeah or it's a bit of feedback from patient, you kind of try and think what it is they want from it, be it a foot or an adjustable part on the ankle or something like that, you get their feedback, you go with what you think fits that criteria and then get them to try it and then see what they think after that before that period ends. "

(ST11- Prosthetist)

Prosthetists saw this increase in feedback as part of the long-term relationship that they built with their patient. Due to the way in which prosthetists delivered care to their patients there was often a lot of opportunity to interact with them, both about the prosthesis and in a more 'people passing the time of day' way so that over time a type of friendship formed. It was often in those cases where a good relationship and rapport had been created that prosthetists reported that a good feedback and discussion from both parties was present which then helped in the prosthetic prescription process.

"So their role is quite important and I'd say it's important as a primary and then it almost gets more important as they get out there and start living life with their prosthesis, that they come back and tell us if things aren't quite how they coped. So you hope that it's a lifelong dialogue, you know, that you can keep talking about what's working and what's not and do it that way."

(ST01- Prosthetist)

"Yeah because you have this lifelong relationship, so even if we're not doing a formal focus group you have that relationship that every time you see them, basically the first thing you ask... 'how are things going?' 'have you any problems?' 'what is it that you need to do?' So yeah, every time you see them you're asking them for... and especially at prescription time, you know. There's not a form or a particular procedure but it's basically that clinical therapeutic relationship."

(ST10- Prosthetist)

6.2.2.4 Family Involvement

Prosthetists identified different aspects of family involvement in the prosthetic rehabilitation process. Usually patients attended their prosthetic and multidisciplinary team (MDT) appointments on their own. There are exceptions to this and in particular prosthetists identified primary trauma patients as being the exception. The reason for this was explored by one prosthetist as being as a result of the sudden nature of a traumatic amputation and the effect that this type of injury had, not just on the patient, but their family as well.

"The traumatic patients I would say will usually bring somebody with them because the trauma isn't entirely on the patient who's lost their limb, their trauma extends

to their family and I certainly think in the case of my young student, he brought his mum with him, you know, she must have been devastated that this had happened and really concerned about her son and he would obviously know that and want the familiarity of his mum there, I certainly would've done at that age. And the other young guy in his early thirties, he brought his wife along with him, clearly again it was a traumatic experience for her, you know, she's got to get used to this person who has had this happen to them."

(ST05- Prosthetist)

In some cases the prosthetist perceived a family member as being the driving force behind demands for certain components which may be inappropriate, and considered them to be 'pulling the patients' strings in a less than constructive way.

"We have an older patient; I don't really know what his reason for amputation and his daughter will write the complaint letters and get him to sign them, and that's the driving factor, you know, so I do sometimes think the patients' relatives and friends might be the ones that kind of stir things up a little bit sometimes."

(ST05- Prosthetist)

"There have been a few occasions when, not with trauma patients, just with very poorly vascular patients, where they have had incredibly poor cardiac function and to fit them with the limbs they were requesting was unsafe. The family members were particularly unhappy about that"

(ST09- Prosthetist)

In other cases prosthetists talked about family members engaging in discussions between the prosthetist and patient in a positive way. In one case where the patient was lacking understanding and unwilling to participate, the family members were able to help the prosthetist with the discussion. In another case engagement of a family member in the discussion added to the knowledge, the prosthetist could then use their input to inform the prescription choice.

"No, I mean, it was all new to them, it was new to her as well. What they were really good at was supporting me [laugh] because she was quite a difficult lady and I think she's suffering post-traumatic stress...she was full of doubt, she was full of anxiety and her family were very good at supporting me because I got quite a hard time,"

(ST06- Prosthetist)

There were also family members who had instigated discussion with the prosthetist about aspects of care that the patient had not highlighted themselves as being important. In cases where the patient had a carer who was responsible for putting the limb on and off then their input was sometimes taken into account when thinking about the prescription and how they would deal with the donning and doffing of that limb.

Key points

1. Prosthetists considered patient feedback as invaluable in informing their prescription choice, particularly as patients became more experienced amputees and were able to articulate what they were feeling
2. Prosthetists reported patients' goals and aspirations as being a large influence in the decision of what to prescribe them with prosthetically, even if it caused them to compromise on maximum functioning of the prosthesis in some cases
3. Changing aspirations were important in the changing of the prosthetic prescription over time
4. Input from the family could be seen as a barrier or facilitator in the prescription process depending on what their driving factors were and how they interacted with prosthetic services.

6.3 Decision

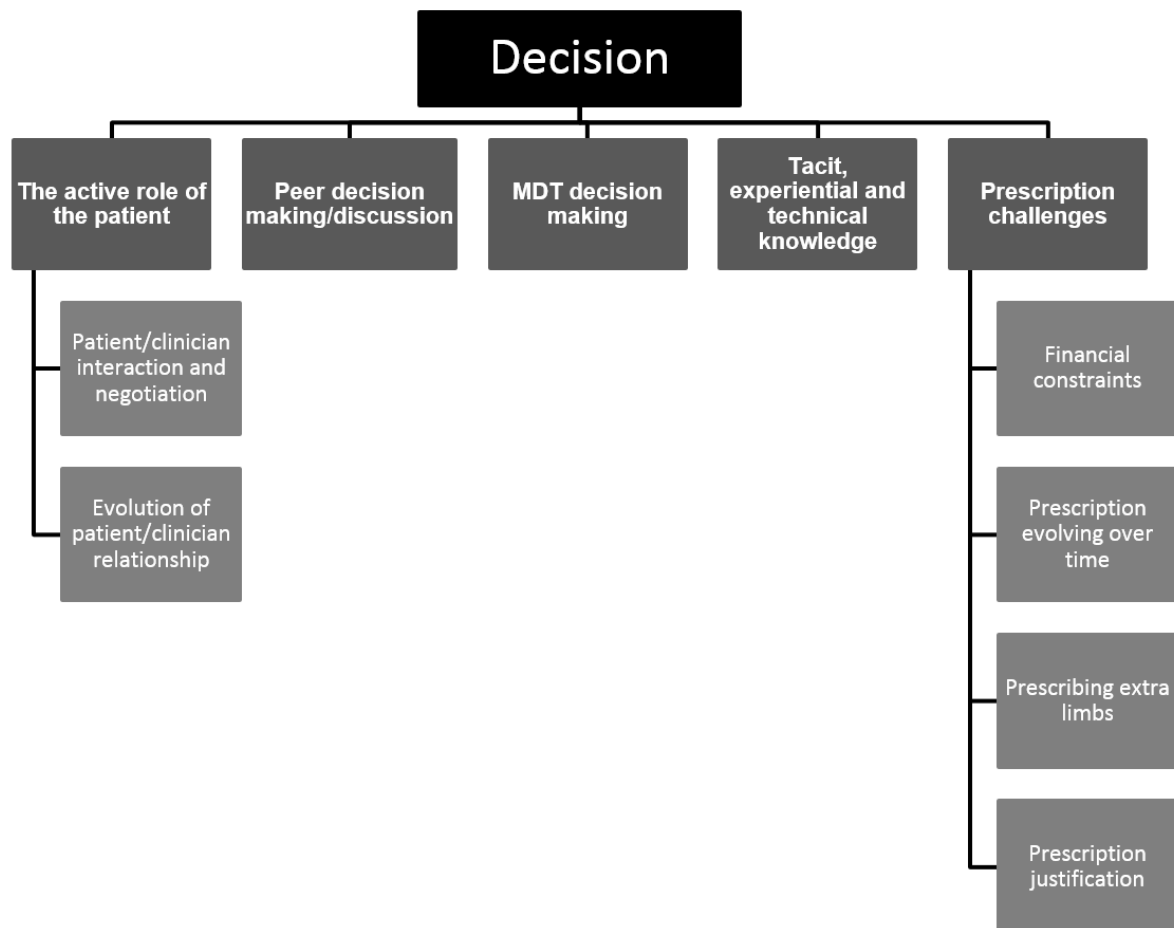


Figure 19: Structure of the decision process

The overarching theme of the Decision captures the process that the prosthetist undertakes after the assessment (judgement) has been completed. As seen above the assessment process allowed prosthetists to make an initial conceptual prescription the choice of components available to them which would meet their patients' needs. The Decision looks at the subsequent steps considered by prosthetists in process of making the prosthetic prescription. These steps included discussion with their peers, seeking advice and discussion from other members of the MTD, considering some of the barriers to prescribing in the NHS and finally the clinical experience and expertise of the prosthetist. In this process the experience and expertise of the prosthetist is seen to be gathered from diverse sources.

6.3.1 The active role of the patient

6.3.1.1 Patient/clinician interaction and negotiation

This sub-theme explored prosthetists views on how different patients interacted with them during the process of prescription and prosthetic rehabilitation. Clinicians identified differences in the way in which patients interacted, patients they identified as being passive during the process, who look to them as the one who held the experience to make that decision and there were those who engaged in discussion with the prosthetist regarding different options. At the opposite end of the scale there were patients who approached the process in a way that appeared be more consumerist.

Prosthetists associated the more passive approach with their older patient group; those who had grown up in an era of paternalistic healthcare (see section 5.5.2). Prosthetists saw these patients as not really wanting to be involved in the process of prescription but were instead happy just to let it happen.

“There are one or... maybe an older generation of patients, they were very used to the medical profession saying ‘you will do this’, they’re not used to the modern open NHS where it’s all happy and yeah, we’re really kind and discuss things with our patients and they’re quite used to the medics coming and going ‘you’ll do this’ and being dictated to. So some of the older generation perhaps want that to happen, I think there’s also a number of patients who don’t have the capacity to make that decision and aren’t particularly interested.”

(ST05- Prosthetist)

“Well they’re just say that we’re the professional I suppose and let us make the decision and say ‘I’m happy to do whatever you tell me’ sort of thing. But yeah I think it is important for the patient to be part of it really, to try and keep them involved in how things progress.”

(ST07- Prosthetist)

Conversely some prosthetists revealed that they were treating patients in a very paternalistic way. In some cases this as appeared to be patronising and underestimating the patient's intelligence.

"it's very difficult for people to grasp prosthetics and what they're looking at and what they're doing, so I do think it's important to discuss it with them and try and give people the chance to understand it, but at the same time sometimes it can very much confuse matters. Yeah, and also we tend to know the products better than they do, we probably know 'this one's rubbish, you're never going to get anything out of this'"

(ST04- Prosthetist)

The more consumerist approach to interactions with the prosthetist was viewed as being quite a new thing which they felt was more prevalent in the younger trauma patient group. In addition prosthetists largely attributed this shift over time to increased access to information on componentry via the internet as well as increased media coverage of military prosthetic patients. This consumerist approach was seen to varying degrees in the cases which prosthetists discussed.

"Whereas, the younger generation, that you may include the majority of your trauma patients into, are a bit more challenging in their expectations, and challenging in their expectations not only of equipment, but service provision, turnaround times, ability to change their own settings on their limbs, and all sorts of things that perhaps challenge our usual service delivery."

(ST13 - Rehabilitation Consultant)

Prosthetists described how they managed this approach. They considered this to be part of the process of negotiation and discussion with patients, which involved a two way conversation between themselves and the patient. However, prosthetists did not always appear to welcome this type of approach from their patients.

"...but there's also that thought in your mind that it's not a shop we're running, you know..."

(ST01- Prosthetist)

"So I mean it is, it's a two way discussion, you know, it's not a sweetie shop, they come in here and demand what they want because it's nice and shiny and glossy. We try and give... if they're expressing a wish for a particular product that they've seen and we think it's not suitable, we'll give them valid reasons why it's not. Likewise if they have something that we've maybe not thought of, we'll try and look into it as well and get them involved in the discussion..."

(ST06- Prosthetist)

While some prosthetists felt that age was a factor in the patients' approach others felt that age was not predictive. One clinician talked about how there was apparently no 'rhyme or reason' as to how the patient would interact and illustrated this as follows.

"It depends on the patient. Some patients want to take quite a lot of control of it, other patients will just sit back accept whatever's given to them and there doesn't seem to be any rhyme or reason, you could put five similar age/similar level patients and they could all be quite different."

(ST11- Prosthetist)

As reported in sections 6.2.2.2 and 6.2.2.3 clinicians valued discussion and feedback from patients as it was considered to be informative in the prescription process. This was reiterated in this sub-theme, that the discussion around the prescription was important even if was not apparent that patients were routinely actively involved in making that decision. The extremes of interaction that the patients brought to the process sometimes appeared to cause difficulties for prosthetists' decision making. As discussed previously a lack of patient feedback could make the process of prescription difficult when patients were unable to articulate how they had coped with the prescription they had been given. At the other end of the scale the consumerist

interaction of some patients caused difficulties as prosthetists talked about inappropriate components being demanded.

Clinicians viewed the involvement of the patient to be about the factors discussed in section 6.2.2.2, about patients goals and aspirations, as it was largely that information combined with the state of the stump which dictated what the prosthetist would prescribe. However, the involvement did not seem to filter down to the point where the patient would be involved in the decision, say, at the level of choosing between two different knee units.

“...as to how much input they have, yes, they can tell you that they would like to get back to gardening or like to get back to a particular sport, but it’s not like I’m bringing out a catalogue and saying, okay, these are the knees or these are the feet or these are whatever is available to you, what would you like to choose? They certainly don’t have an input that way.”

(ST17- Prosthetist)

It seemed that the general view of the prosthetists on the right amount of involvement was based around discussion about the possibilities of what could be prescribed, the pros and cons of those options, and input from the patient regarding the activities they wanted to be able to achieve, their goals and aspirations. Prosthetists valued those contributions from the patient which helped to guide their prosthetic prescription but they intimated that ultimately the decision would be theirs.

“Oh it’s hugely important and it varies from individual...but other people they’re more of an inclusive part of the team, so they’ve come in and identified an issue and then we are trying to solve that issue rather than them specifically saying ‘I want this particular one’. But if they come in and say ‘I’m having trouble when I’m cycling’ or whatever, then we say ‘okay, well that’s a problem, how can we fix it and is there a way round it?’ So obviously they’re very important, the way they do it can be different but at the end of the day they wear it, so as long as we’re giving them something that’s safe and appropriate and effective, then certainly their choice is very important as to what’s important to them.”

(ST10-Prosthetist)

Prosthetists also talked about patients' involvement and interaction with the service changing over time and that this was a result of them having more experience and after wearing the limb for a period of time that they were then able to explain more to the prosthetist. Again this evolution of the interaction was closely linked with the patient's ability to feedback as they become a more established amputee.

"Probably not to start with, but certainly if people come back and you can kind of get the feel that they're not perhaps too happy with what they've got, I might say to them, okay, what is it, because you've clearly got something in your mind that you're maybe thinking about, what is it that...what is it you fancy, and they'll quite often say, well, I saw this, saw on telly or I saw somebody else with this and you can say, okay, let's think about that, is that going to be good for you, is it not going to be good for you."

(ST17-Prosthetist)

Overall the data from prosthetists showed that in the majority of cases patients were not involved to the point of deciding themselves between options. However, there were a small number of isolated cases where this did seem to happen. This could occur when the prosthetist had narrowed down the possible options but had identified more than one option which would be suitable; it was in these cases that the patient was invited to make a choice between the two options. These choices did seem to relate to the softer aspects of prosthetic prescription for example on cosmesis and socket choice. In addition it was a much framed decision and by the time they asked the patient to make a choice, the majority of options having already been excluded.

6.3.1.2 Evolution of the patient-clinician relationship

Throughout the interviews with prosthetists there was reference made to the unique relationship that prosthetists felt they had with their patients. Prosthetists talked about the longevity of their relationships with patients describing them as being 'for life'. Prosthetists recognised that nurturing a good relationship with their patients was useful in assisting with the process of their treatment and getting the most out of their prosthetic limb.

"...these patients are patients for life so you really have to have a good sort of working relationship with them. I hate when I hear patients say 'my Prosthetist won't listen to me' you know, touch wood we don't really have that here, it's been said in other centres but we have..."

(ST06- Prosthetist)

"I wouldn't choose something I had never used before because I'm wanting them to have a bit of confidence in me and to be able to wear what I make and not be trailing back and back and back on the first go, because sometimes when you try new things you just don't get them right the first time and people...both sides have to be patient, so I probably would be looking for something that I knew I would...I can do quite well."

(ST17- Prosthetist)

Continuity of care was described as one of the reasons why this relationship could be formed. Prosthetists reported that they had a workload of patients so they had 'their own' patients who they followed throughout their time as a limb wearer. Due to the environment and process of prosthetic provision prosthetists spoke about the long period of time that they could spend with a patient during the course of an appointment or series of appointments. Prosthetists talked about how this reinforced their relationship with their patients it allowed them the opportunity to get to know their patients beyond the scope of prosthetics. What they reported was that it was within this therapeutic relationship that they were able to explore patients' goals and aspirations as their patients evolved over time and the importance of that for their prosthetic prescription.

"So you hope that it's a lifelong dialogue, you know, that you can keep talking about what's working and what's not and do it that way."

(ST01- Prosthetist)

In the trauma amputee group this relationship had even longer to develop as they were typically much younger than the general amputee population. Prosthetists talked about seeing

these patients move through different live stages as well as their progress as an amputee during the course of their life.

During the course of the interviews prosthetists spoke a lot about managing patients' expectations, those relating to what they wanted to achieve activity wise in the future, what they could expect from their prosthetic limb as well as around what components they were ultimately prescribed.

The management of patients' expectation around their goals, aspirations and activity levels was predominantly spoken about with respect to primary patients who were keen to get straight back to how they were before their amputation. However, as discussed in section 6.2.2.1 prosthetists tended to err on the side of a more basic prescription for a new amputee. This could be a point at which prosthetists had to negotiate with the patient and manage their expectations, particularly with primary patients around the subject of what they were going to be able to achieve with the limb. The discussions they reported having with primary patients were around the benefits of this type of prescription for them as a new limb wearer learning to walk with a prosthesis. It was made clear that their prescriptions would be reviewed over time and any necessary changes made.

"Obviously we have to talk to them if their expectations are not feasible, but then we do sort of goal setting and chunk it down, that sort of thing."

(ST10- Prosthetist)

"He was involved a lot in it although he didn't necessarily agree with the decision. He had a lot of input...he gave us the opinion on what he wanted from it, but as I say, bear in mind he was a primary amputee, we had to try and manage his expectations as well."

(ST11- Prosthetist)

Prosthetists indicated that some patients attended clinic expecting to be prescribed different components because they wanted to participate in further activities such as running. This was another point that prosthetists saw as requiring discussion and in some cases management

of expectations. They indicated that there needed to be a level of education so that patients understood that they did not necessarily need a specific component or limb to allow them to do a specific activity.

"Yeah there is a perception amongst patients 'I want one of those legs you can run on' 'well are you running at the moment?' 'well no' 'well you need to be able to run before we can give you one because the leg's not going to run for you' and there is that real 'I can't do this because you're not prescribing me the type of equipment that's going to allow me to do it' that's not true...He could still try it on a normal one"

(ST05- Prosthetist)

"And I wonder if that's the way that it's portrayed to them. You know, you can get running prosthesis so you assume, oh, well, that means I can't run on these ones, but, of course, you can. There's lots of prosthetic feet, in particular, that you can use for all sorts of activities...And, I suppose, even your most basic prescription...you might not run amazingly, but you could give it a decent try...Yes, we do spend a lot of time just managing that expectation..."

(ST14-Prosthetist)

Prosthetists associated much of the negotiation with the more consumerist interaction of patients with the service. Discussion commonly resulted when patients came in asking for something specific. This discussion with the patient was framed by the prosthetist as covering several aspects; they asked why the patient wanted that particular component, discussed if there were any activities that the patient was involved in which indicated it was needed and what the pros and cons of providing it would be for them. In cases where the requested component was inappropriate prosthetists talked about explaining to the patient why this was the case.

"...but it gets very difficult when they start to dictate it... I mean, I've been qualified about 16 years now and even in that time the patients' education level as to what's available has increased because of access to the internet and things like that, and

I do think they need to be involved in that discussion but it would be through our advice that you would hopefully... you should be able to talk it through with your patient and think 'well I think this is the best thing for you because of these reasons and although you're saying you want this, I'm not sure that's appropriate for you at the moment, let's try this to start with and see how we go', so I think they need to be involved in that discussion, I think it is quite important."

(ST05- Prosthetist)

Prosthetists reported that these discussions could be invaluable in maintaining a good clinical relationship with their patients as well as providing a good platform to explain why they had or had not received a specific component. They talked about the importance of making patients aware that their prescription would be reviewed regularly and adapted as required.

In a small number of cases communication breakdowns were discussed and the impact that this could have on the process of prescription. Some cases illustrated that discussion could defuse a situation where the patient was unhappy with their prescription while in other cases discussion did not work and there was a breakdown in the patient-clinician relationship.

"Yes, have had that where patients have been unhappy, but then it can be discussed. So I would like to think that nobody leaves unhappy."

(ST01- Prosthetist)

"...she complained again formally that things weren't going as she wanted them to, so again we... by this point we were considering a gait lab and multi-disciplinary team approach to her anyway...so we got more members of the multi-disciplinary team on board, we gait labbed her and she had said at that point 'I want you to do what you think will help me'. So at that point I was able to say 'right well fine, this is the knee'...She handed it over and made that decision and she was compliant with the physio regime that we had put in and actually I think her gait has improved, or certainly improved at the time when we were fitting it, she's not been back to allow me to check up on what's happened, and when she's come in she said to

me 'don't watch me and don't change anything, I just want a minor repair on another leg' not even the leg that we were making."

(ST05- Prosthetist)

Key points

1. Differences in how patients interact with prosthetic services affected the level of involvement that different patients have in the prescription process.
2. Prosthetists resistance in some cases to the changes in patients' interaction with prosthetic services.
3. Negotiation between the prosthetist and patient affected what was ultimately prescribed.
4. The changing relationship between prosthetist and patient affecting the prosthetists understanding of the patients' needs and therefore affecting the prescription choice.

6.3.2 Peer discussion and decision making

Commonly prosthetists discussed the interaction they had had with their peers as part of the prosthetic prescription process. During the interviews each prosthetist spoke about occasions where they had discussed patients' prescriptions with other prosthetists in their centres. The structure of the way that prosthetists in this group interacted with their peers varied. Some reported that there was a structured forum for this type of interaction, in other centres this happened on a more *ad hoc* basis as and when members of the team felt that it was needed, finally in others there was a combination of the two.

"...we're a very good team for the most part of having informal discussions over a cup of tea about somebody that they've had or somebody will come in the office 'oh I've got this patient that's coming in, I'm not quite sure what to do with it?' and we will then have this open discussion about it, almost to the point where I kind of feel formal meetings are perhaps not always required in the office because things get discussed quite openly and regularly."

(ST05- Prosthetist)

"...we have discussions between the three... well there's actually four Prosthetists but there's always three here, or mainly three here, yeah, we'll have case conferences on an ad hoc basis...if we haven't used a particular product but I

know [other prosthetist] has, I'll speak to them about it and that's the same for them..."

(ST06- Prosthetist)

"It can be both really but we try to make it a bit more formalised, we try and have it in a meeting where we are all able to have the time to discuss something, but sometimes you're in a situation that you've got to come up with something quickly and you go and ask the rest what they think."

(ST07- Prosthetist)

Prosthetists talked about the function of the discussion varying depending on the factors which led to their uncertainty in the decision. Some talked about this uncertainty being associated with their level of experience; this could be associated with experience of a certain activity, or experience of a specific component which they were considering prescribing. In these cases prosthetists did not identify that this happened when they did not know what to prescribe but rather it took the form of seeking advice on options which they had identified as a possibilities for their patient or seeking advice on a component which their peers had found to suitable for a certain activity. In general, a lot of this discussion arose as a result of seeking out others' opinions on the prescription choice, either with the purpose of corroborating what they had already decided to prescribe or to see if any of their peers considered there to be a better or more appropriate option.

"So we discuss individual experiences, so 'I tried such and such a foot and this is what they said' or maybe 'I tried three feet on one patient and this is what they said', or might come at it from the other way and say 'I need a knee that does this, this and this, what does everyone think, what have you done?' you know, so there's a fair bit of that goes on. It's a good team. A consensus I suppose you could call that with a very small number."

(ST01- Prosthetist)

"we try and work as a team if you've got a patient who you've got a particular prescription to come up with, we try and all discuss it together and try and make decisions based on everyone's experience as well."

(ST07- Prosthetist)

In some cases they talked about the need for discussion with their peers being based upon the cost of the components they wanted to prescribe.

"And in fact we do have a loose policy that would say that if you want to order anything over a certain value, let's discuss it, not so much to get approval for it but so that we all understand why and when we're going to make this sort of prescribing."

(ST01- Prosthetist)

"It is quite difficult because there's nobody above me that knows enough for me to discuss it with, but I'd like to think if I was considering spending a good amount of money on it I would probably have had an informal discussion in the office about it..."

(ST05- Prosthetist)

The majority of prosthetists talked about this discussion occurring within the prosthetic centre in which they worked. They talked about this being particularly beneficial due to the prior knowledge that their colleagues had of the patient that was being discussed and because this process could happen in such an informal way as and when it was needed.

"suppose the difference at the local level is that your colleagues know exactly the individual you're talking about, so I suppose there's not the same need to go into as much detail as you would need to if we were meeting with Prosthetists from other centres and doing that we'd obviously have to give the full history, whereas here we would all roughly know what had gone on in the past, yeah."

(ST01- Prosthetist)

Informal discussion outwith their own centres was also recognised by prosthetists as occurring when considering prescription decisions. This wider discussion included prosthetists talking to friends who were prosthetists working elsewhere and asking them what they would do in a hypothetical situation. In other cases prosthetists talked about their peers identifying a prosthetist outwith their centre that had experience of a patient requiring components to do a specific activity such as skiing and seeking them out for advice. One prosthetist spoke about online forums in which some of their colleagues were participants (mostly US based) where prosthetists posted problems asking for feedback and advice. Finally, one prosthetist spoke about there having been a Scottish prosthetist practice development network set up by Quality Improvement Scotland with part of their remit involving evidence for the prescription of components.

Prosthetists identified that this discussion allowed them to take their peers additional information and experience and use it to enhance their decision making process in order to benefit their patient. Prosthetists did not appear to feel that they worked alone but that they were part of a team which was helpful and supportive in improving prescription choices. What it also showed was that the decision on the prescription was not something that had to be made immediately but that there was time for the prescribing prosthetist to seek further advice before the decision was made, this would support the theory that there was enough time for the prosthetist to make a more rational choice on the prosthetic prescription.

Key points

1. Prosthetists are able/allowed to make autonomous prosthetic decisions but they can be seen to seek advice from their peers
2. They seem to value the idea of consensus and a joint decision with their peers – they are happy to look beyond their own knowledge to provide the best prosthetic prescription

6.3.3 Multidisciplinary team decision making

Prosthetists are central in the prescription process however, throughout the interviews prosthetists discussed the multidisciplinary team that they work within and how this influenced their prescription choices. The way in which these interactions occurred is explored in this theme as well as what the other members of the MDT feel their contributions to the process were. This theme looks at the involvement of an interaction between the members of the multi-disciplinary team in the process of decision making from their different perspectives. It

also explores the ways that these groups of clinicians feel that they interact with each other and their importance in the prosthetic prescription process.

6.3.3.1 Prosthetists consultation with the MDT

Prosthetists saw themselves as autonomous decision makers in the prescription process. Despite this they talked about instances during this process that they would seek further information and opinions which had an influence on their prescription choice. The clinical group that prosthetists consulted most regularly with was physiotherapists. They talked about two levels of information exchange with physiotherapists. In the first they sought information which would help them choose between the options which they had already identified as possibilities. In the second they made the options that they were considering explicit to the physiotherapist and asked directly for their professional opinion of the appropriateness and suitability of those options. They described these consultations as an exchange of information between themselves and the physiotherapist.

Most commonly a consultation was sought when the prosthetist was considering what type of knee joint to provide for a patient. In one centre it was indicated by both clinical groups that patients were referred to prosthetics by the physiotherapist, referral paperwork contained information from the physiotherapist which was pertinent to the prosthetist. In trans-femoral cases this included their recommendations for a classification of prosthetic knee joint. As discussed in section 6.2.2.1 prosthetists also talked about getting feedback from physiotherapists about primary patients' current activity level and forecast future activity levels.

Prosthetists felt that the information they could gain from the physiotherapists was invaluable; they appreciated that prior to prosthetic fitting primary patients would have a closer relationship with their physiotherapist than they had with them. This meant that physiotherapists often had important and pertinent information to pass on to the prosthetist which the patient may not have thought to tell the prosthetist at that point. Prosthetists spoke about this meaning that they were able to get a fuller understanding of the patient with the help of the physiotherapist. One prosthetist also talked about meeting with the physiotherapist and the patient prior to an official referral. As a result they were able to see the patient undertaking pre-prosthetic physiotherapy and speak with the physiotherapist and the patient about how they were getting on at that stage and to consider how this could impact on their prosthetic prescription and rehabilitation.

The way that prosthetists talked about the process showed that they had belief in their abilities to prescribe effectively and being the ones to make that decision. In some cases they spoke about bringing more difficult cases to the MDT meeting to be discussed, e.g. where there had been a breakdown in the relationship between the prosthetist and the patient and they felt they needed to take a more MDT approach to solve these issues.

“...we’re quite lucky here that our prescription is kind of led by the Prosthetists. Obviously we discuss it with the head of prosthetics that what we’re doing is okay, but generally when it comes to prosthetic prescription we’re in control of it and we’ll take the advice of the physios and the consultant and the nursing staff.”

(ST11- Prosthetist)

Physiotherapists’ views mirrored those of the prosthetists about their role in the prescription process. They talked about feeding back to the prosthetist about patients’ capabilities around the time of their primary prosthetic prescription. They reported that prosthetists would discuss with them how the patient was getting on with their pre-prosthetic rehabilitation and what they are able to achieve or not, and they understood that their feedback at this stage could influence a patients’ prosthetic prescription. As a result one physiotherapist talked about pushing the patient to achieve as much as they could pre-prosthetically. As was alluded to by prosthetists, physiotherapists saw themselves as uniquely able to assess and understand where the patient had reached physically and what they might be able to achieve in the future, i.e. after prosthetic fitting. This knowledge was gained through the time they spent with the patient both pre and post amputation prior to prosthetic fitting meant that in many cases they had insight into that aspect of the patient that the prosthetist will not have at that stage, therefore any information that the physiotherapist had gained from the patient during this stage was important in the process of prosthetic prescription. Physiotherapists identified that they talked extensively about patients activities, what they wanted to achieve and their personal habits, all of which was information that could be passed on the prosthetist to inform their prescription.

Physiotherapists most commonly identified being approached by prosthetists for advice in trans-femoral cases. This could be where the prosthetist was in the process of choosing which type of prosthetic knee component to prescribe. Commonly this was seeking the physiotherapists’ opinion on the use of a free or locking knee joint for a specific patient or the

weight of the component itself and seeking advice from the physiotherapist on a patient's ability to cope with different aspects of a specific prescription option. One physiotherapist talked about working closely with a prosthetist to determine what the best foot prescription would be for a specific patient.

6.3.3.2 *The Consultants role*

The prosthetists interviewed in this study did not consider consultants to be central to the prosthetic prescription process in Scotland. However, some reported that they had previously worked at centres in England where consultants had led the prosthetic prescription process. Others were aware that this was still the structure of prosthetic prescription within various prosthetics centres in England. One prosthetist spoke of working in a centre where all prosthetic components were prescribed by the consultant and prosthetists were considered to be 'fitter'. Prosthetists characterised consultants in their centres as playing a more medical role in the care of prosthetic patients, considering aspects such as stump condition, grafting, skin breakdown and pain.

This view was mostly reflected by the consultants in this study. They talked about making suggestions to the prosthetist about some aspects of the prescription they would like to see in a general way, i.e. the use of a liner or tissue friendly material against the skin in a patient with grafting or suggesting that they use a certain category of knee joint, a free knee for example. They indicated that they did not see it as their position to be making fine detail decisions on specific components but more to talk to the prosthetist about broader features of the limb. They also noted that they could have more input in some cases, for example, if the prosthetist thought that the stump required revision surgery to facilitate prosthetic fitting they could feed this back to the consultant for consideration. Similarly another consultant talked about their involvement being around medical management of the stump, i.e. excessive pain, phantom limb pain or skin breakdown. This consultant discussed their role as being part of the MDT during the primary prosthetic rehabilitation phase, keeping the patients' medically fit and to help the MDT maximise the patients' functional outcomes. They talked about how after a patient was discharged from the initial treatment episode their day to day care fell to the prosthetist.

"I think it varies significantly depending on the individual. As I say, some of the – and not always just the older men, but you know, I think it depends on their expectations and how they deal with medical professionals, as in the team. That

some people will be asking lots of questions, and wanting to do lots of different things. Whereas, other people will say, yes doctor, no doctor. I think it's very different and it's not necessarily an age thing."

(ST13-Rehabilitation Consultant)

There was the impression from other members of the MDT that their role was to provide advice and information but that it was the prosthetist that had the expertise to make the prosthetic prescription decision.

"I very much don't see my role as telling a professional prosthetist, you need to do this. That's not the role here, I guess I see my bit as taking the clinical need to the patient and trying to facilitate that, not do anything else."

(ST13-Rehabilitation Consultant)

6.3.3.3 Multidisciplinary Team (MDT)

During the rehabilitation of primary amputees the idea of MDT working was strongly adhered to. In each of the centres involved in the study there were reports of organised MDT meetings which included, consultants, prosthetists, physiotherapists, occupational therapists and nurses. The organisation of these meetings differed from centre to centre but the idea of knowledge exchange and discussion was identified in each. Most reports of these meetings were that it was more difficult or complicated patients which were discussed at these meeting. Participants from each centre indicated that even without specific MDT meetings there were close enough working relationships between prosthetists and physiotherapists for discussion on individual cases to occur when needed.

MDT working was conveyed by all of the clinical groups as an important part of amputee rehabilitation. The functioning of the MDT differed from centre to centre depending on the organisation of the clinical teams and their proximity to each other within the hospital. Those teams which physically worked closer to each other put more emphasis on the importance of MDT working and where they were further apart this was seen as a barrier to more integrated MDT working. At one site physiotherapists stated that the close working relationship between the prosthetists and the physiotherapists had taken a lot of time and effort. Some noted that an increase in communication between prosthetists and other members of the clinical team

had occurred when prosthetic services moved from contracted to in house NHS services, prior to that they felt that prosthetists worked in a very insular way.

Key points

1. Prosthetists understood clearly the influence that physiotherapists had on their prescription choices for primary amputees based on their knowledge and expertise on the patients current and expected future activity levels.
2. Physiotherapists were aware of the influence they could have over the prescription choice based on the information that they gave to prosthetists at the time of the primary prosthetic prescription.
3. Prosthetists who had previously worked in England, and had friends who still did, noted the difference in the level of input that rehabilitation consultants had in prosthetic prescription between Scottish and English DSCs.
4. Other members of the MDT saw the prosthetist as being the one with the level of knowledge, experience and training to make the prosthetic prescription decision, both the physiotherapists and consultants saw themselves as there to provide advice to help guide or assist that decision by providing broader information on the patients' health and abilities.
5. Consultants identified themselves as participating in the MDT but were less involved in the process of prescribing prosthetic components. This was reflected by prosthetists and physiotherapists.
6. The importance of members of the MDT physically working closer to each other.

6.3.4 Tacit, experiential and technical knowledge

This theme explored the other sources of information which prosthetists identified as being available to them during the process of prosthetic prescription and also how they utilised these sources. Most of what prosthetists identified as informing their prosthetic choice centred on their own experience and knowledge, the experience and knowledge of their peers and information gathered from the patient and other members of the MDT. This theme explored where and how prosthetists gained knowledge of the components available and how it was fed into the prescriptions they provided.

6.3.4.1 *Component knowledge*

Prosthetists talked frequently about their knowledge of specific components and that this had been gathered over years of using these components; they considered them to be 'tried and tested'. These are the components which made up the majority of their prescription choices.

"I'd say the majority of our stuff will be things that have been used here for a long, long time, you know, we've got staff experience expanding nearly 40 years so they'll know what's good and what they've used in the past and what's bad"

(ST04- Prosthetist)

They also discussed this knowledge and preference in terms of ranges of prosthetic components, their experience of a particular product range and how this could make them more likely to try and trust new components which come out as part of that range.

"Yeah, probably only what's in my head. I wouldn't be going away and investigating new componentry every time I was making a new decision, no. It would probably be what was in my head, what I know the store has here and things that I know I'm good at and work well for me, limbs systems that work well for me."

(ST17- Prosthetist)

Prosthetists reported that through a combination of their own knowledge and experience as well as that of their peer group which gave them an evolving understanding of available components which they drew on to benefit their patients during prescription.

"but I think experience with different products, I mean, you know... we do, we're quite lucky here that we are an NHS centre, we're not bound to any particular manufacturer so we do use a wide range of products, so we do have a wide range of experience in various products and we do feed off each other, so we're always building our experience up."

(ST06- Prosthetist)

6.3.4.2 Company representatives/prosthetists and trial components

When talking about considering newly available components in a prescription of which the prosthetic team had no experience they reported seeking information from the manufacturer. Different companies offered different forms of training on the componentry that they produced. Some companies asked that prosthetists undertook specific training courses offered by them in order to become certified in the use of a specific component. More commonly prosthetic

companies offered information and guidance on the use of their components, prosthetists were able to seek their advice either if they were considering using a component or if they had purchased a component and were having difficulties in fitting it. Most prosthetic companies employed their own prosthetists who were trained in all of their companies' components; these prosthetists could be asked to visit specific prosthetic centres to provide expert advice on the fitting and optimisation of new components.

"I mean, I'll contact the companies and ask them for advice. If you've fitted a knee or something and you're having problems with it, and you can't...it's making a noise and you can't think what it is. You're just not happy with it. I'll contact them and they'll come up and help."

(ST12- Prosthetist)

The other service which prosthetic companies offered was the use of components provided on loan, these are known as 'loaner units' provided to the prosthetist to test on their patients and use their feedback to decide if it was something that they wanted to be provided with in their new prosthetic prescription. These loaner units could be used with established amputees as a method of trial and error, one prosthetist talked about narrowing down the choice of prosthetic feet to three or four and testing each of those foot components on the patient and using their feedback to provide the most appropriate one. The use of loaner units appeared to be applicable when prosthetists were considering more expensive components that they would test before purchasing as components cannot be transferred from one patient to another after use.

6.3.4.3 Literature

The prosthetists felt that there was a lack of research literature that they could use to help to inform their prescription choices. One prosthetist identified that there was not enough evidence from the literature available to justify particularly expensive components.

"...we don't have sufficient cost effectiveness evidence...There is evidence to show that in certain aspects, for example, the C-leg, does have benefits over different types of knees, but there's no...there's not enough evidence to show that that difference, or that little bit of benefit, is worth the, what, ten, 11, 12 thousand

pounds worth of difference in the cost of it when you look at Genium that's even more. That's absolutely a massive cost difference."

(ST14- Prosthetist)

Prosthetists also identified their issues with the quality of the available literature, both in respect of study design and also the possible biased nature of the research evidence. There was also a feeling that the volume of research evidence in prosthetic components is skewed towards higher end, more expensive components and did not focus on the components which prosthetists were making decisions between on a day to day basis.

"There's hardly any research behind most prosthetic products. Huge amount of research in... well not huge but there's a significant amount of research in quite fancy products that come out, it tends to be the companies that have done their research so you've got to be careful with it, but it's always quite dated, it always takes a wee while for it to come through"

(ST04- Prosthetist)

One item of literature which was designed to assist in the prescription process was discussed by a number of prosthetists as being too general in its approach. The RSL Steeper prescriptions guidelines are spoken about as identifying which class of component would be clinically appropriate for different groups of patients but did not have the detail to identify specific components (RSL Steeper 2011). Another prosthetist talked again about the biased nature of the evidence which was used to create these guidelines.

"It's difficult to... so we have quite generic, you know, like the... is it Steepers did the... So you have those generic sort of guidelines, so to a point you can say 'our consensus of opinion is any of these things will be clinically appropriate or won't be clinically inappropriate' and then it's how do you really get down to the wire of 'is that one better than that one?'"

(ST10- Prosthetist)

“And a lot of their stuff is evidence based and I think that's a hard thing cause a lot of things, C-Legs especially, a lot of the evidence based stuff for the C-Legs, you suddenly go through all the references and it's kind of backed by Ottobock in some kind of way and it's difficult and that's kind of the case a lot of the time.”

(ST11- Prosthetist)

While several prosthetists talked about wanting more research evidence there was one prosthetist who indicated that they saw that there was a lack of evidence but despite this no patient had ever requested evidence to indicate if their prescription was the best thing for them. This corroborated data that indicated that prosthetists did not identify research literature as assisting in their day to day prescription choices although there was a feeling that it would be nice to have some research evidence behind their decisions. In the absence of good quality research prosthetists talked about relying on their experience to make these choices and also in justifying these decisions. One thread which runs throughout this sub-theme was the impression that prosthetists felt that the component research available to them was heavily biased by different prosthetic manufacturers.

One other type of literature which prosthetists talked about was information provided with each component which had the technical specifications, features of the components and the activity level for it was graded. Prosthetists also regularly received promotional literature from prosthetic manufacturing companies about upcoming and existing products. From that perspective prosthetists were exposed to quite a commercial aspect of prosthetic care.

Key points

1. Literature was seen as lacking but there was a feeling that prosthetists did not view this as particularly affecting their day to day decisions, they were able to draw on other aspects and information to fill this gap.
2. Prosthetists seemed confident in using their personal experience and the experiences of their peers to drive their prosthetic component choices.
3. Trial components were useful but took time and resources in the form of prosthetist and technical time to utilise.

6.3.5 Prescription challenges

6.3.5.1 Financial constraints

Data gathered from prosthetists across all three study sites reported a range of components which cannot currently be prescribed through the NHS in Scotland. Components included on this list accounted for the most expensive prosthetic components available on the market today, including microprocessor ankle and knee joints and 'high end' prosthetic feet. All prosthetists were aware of the components which they were unable to prescribe. They reported that this list was dictated by budget as well as a lack of evidence to support the cost effectiveness of these high end components.

"...yeah it's mostly budgetary but I think you have to have clinical evidence and if that evidence isn't... if you can't really back that evidence then it's hard to justify the extreme cost from, for example, a micro-processing knee compared to a high end hydraulic knee."

(ST11- Prosthetist)

When specifically questioned on the factors which they saw as affecting their prescription choice cost was commonly raised along with the clinical factors discussed earlier in this chapter. The cost of prescriptions was highlighted by some prosthetists as a factor which was always at the back of their minds and their understanding of the important role that cost could play in prescription.

"I suppose cost does come into it as well usually, that's you're aware of the cost of things you're prescribing too."

(ST07- Prosthetist)

This could be seen in the responses from prosthetists to the questions around the perceived constraints on prescription that they had experienced. In response to these questions they spoke frequently about cases in which financial restriction or the prescribing restrictions spoken about above prevented them from prescribing their first choice.

“Certainly budget was one thing because he’s a transfemoral, I could’ve given him a microprocessor knee, you know, that’s obviously one option and we chose not to for just the fact that well actually it’s so expensive and we haven’t tried everything else yet,”

(ST10- Prosthetist)

There was awareness from prosthetists that there was a ceiling on what they could provide financially. Aside from the list of components which they were unable to provide there was a process of justification if they wanted to prescribe something which was considered more expensive than normal. In these cases, prosthetists reported the need for more discussion and involvement from both their peers and superiors in the process. Linked to the process of peer discussion and decision making they talked about discussing options with their peers to identify less expensive alternatives. If the conclusion of these discussions was that there was no cheaper alternative then they could seek higher permission to provide that. Decisions relating to finance were made on a case by case basis and as a result prosthetists were required to make a case to justify more expensive prescriptions. They suggested that it was rare for a case to be refused but that this process provided a basis for discussion on why certain prescriptions were permitted and in what circumstances.

A different perspective on finance could be seen from both service managers and lead prosthetists. Those interviewed early in the data collection period reported uncertainty about the funding that would be available for veteran amputees joining prosthetic services in Scotland. They reported that at that stage, components for any amputee veteran patients were being paid for through their existing funding structure. There were fears that if this situation continued it could have an impact on the prosthetic component provision for their civilian patients.

“But the component, cause there has to be something for the component cost, otherwise the negative impact on the rest of the service will be quite substantial, because the individual components themselves are so dear.”

(ST02 – Service Manager)

Among lead prosthetists, like the service managers, there was confusion about how the care for amputee veterans was going to be handled. One lead prosthetist expressed concern about being both management and financially motivated because without being given an increase budget or ring fenced money for amputee veterans that this would result in them having less to spend on the rest of their patients which would be inequitable. The additional cost was seen as consisting of the cost of components and the increased time required to fit some of the more complex components. These lead prosthetists talked about their roles as including the management of the prosthetic budgets and its allocation. From their positions as service managers and lead prosthetists it could be seen that the resolution of the funding for veteran prosthetics was a key aspect of their management of care delivery.

Despite the apparent constraints of finance on prescription, the data suggested that prosthetists did not feel that this was detrimental to their day to day practice. This could be attributed to the types of patients who would usually require higher end components not being average amputees in the UK. Budget was not raised as a direct issue in any of the units in which this study was carried out, but rather that it was something which the prosthetists working within the centres were aware of and that there were systems in place to deal with prescribing components that were considered to cost more than the norm. One prosthetist noted that while they felt that the restrictions on prescription costs within the NHS in Scotland did not affect their average patients, that it may be more restrictive for military and trauma patients. This again would be linked to the types of patients, their mode of injury and their activity capabilities. They noted that beyond the short list of components which they were unable to provide there were a large number of other options which could be utilised. There was a feeling that more expensive components might be considered more often initially, not necessarily because they had had been proven to be the best, but because these were the types of components which were associated with more publicity, in both the media and through manufacturer advertising.

The uncertainty which was voiced by service managers and lead prosthetists at the beginning of the data collection period over funding for amputee veterans was not so evident in the interviews carried out at the end of data collection. During that time a funding structure was in the process of being developed and implemented giving prosthetic services in Scotland access to additional funding for amputee veteran care as well as access to additional funding for eligible civilian amputees, allaying their original fears.

6.3.5.2 Prescription evolving over time

Earlier themes touched on the trial and error aspect of prosthetics prescription. This resulted in changes in prescriptions over long periods as the prosthetist continued to match their prescription choices with the changing needs of the patient. The data in this section highlighted the knowledge that the decision on what to prescribe for a patient does not have to stand for a long period of time and was expected to change. One prosthetist talked about it not being a life and death situation and that they were fortunate to have the opportunity to re-evaluate their prescription choices throughout the lifetime of their relationship with their patients. They did not think about this re-evaluation as being the result of a wrong decision but as a shift in the factors which had originally affected their prescription choice.

Prosthetists discussed different indicators for making a prescription change. This could be part of the discussion with their patient around what they could or could not do with the prosthetic limb and if there were any ways in which they felt the limb was restricting them. Alternatively they reported an indication for change being a patient attending clinic with extensive prosthetic wear over a short period of time, this indicated to the prosthetist that their patient was doing more with their limb than it had originally been prescribed to withstand. Conversely, prosthetists talked about patients who reported to them that they were finding it difficult to walk with their current limb either because their activity level had decreased over time or that they had been provided with a component which had been prescribed thinking that the patient would achieve a higher activity level earlier than they had. This is an example of prosthetists misjudging the expected activity level that was discussed earlier in this chapter. Each of these situations provided the prosthetist with the indication that a change in prescription was required. Prosthetists reported that changes in prescription could happen at any time in response to the needs of the patient.

6.3.5.3 Prescribing extra limbs

In addition to the evolution of the prescription, prosthetists revealed that there were circumstances where an additional limb could be prescribed if the patient was engaging or planning to engage in an activity which would require a more specialised limb. This was closely linked with a patients aspirations and activity levels, as a result, providing a limb for a specific activity or level of activity was patient led. In these instances the patient had to ask for an additional limb as they were not offered routinely. Most commonly, prosthetists reported that

patients asked them for a water activity/ showering limb or a running limb. In the case of the showering limb or water activity limb, prosthetists talked about the prescription of this sort of activity limb as being straight forward. The safety of the patient using this type of limb, could easily be assessed by the occupational therapist, and the cost of these types of limbs was very low.

"...if somebody says 'I want a leg for the shower' you've got to assess their safety first because the shower legs... they're better but they could go skyting over the shower, so you sort of... if I think you're a bit unsteady I might question it, but generally they're okay and the only reason that it is because they're dead cheap [laugh] and that's terrible but it's true!"

(ST04- Prosthetist)

When asked to prescribe a limb or components for an activity such as running, prosthetists most commonly reported wanting to see some 'buy in' from the patient in attempting a specific activity before they committed to spending the money on components which would help them excel at that activity.

"...they have to have shown that they're actually going to do it cause I get so many people 'I want to run a marathon' 'have you ever ran before?' 'no' and you can't justify, you know, a two and a half grand foot and say 'well you might try'..."

(ST04- Prosthetist)

"Because I think quite often patients will look...will say they want to do something and will expect the hardware to do it, whereas I think everything they get, they can do with a very basic leg, if you want to call it that and they might break that very basic leg doing this high activity and then you'd say, well, that's fine, we're beefing this up for you... but I think people wait to be given a high tech thing before...it would be like me saying, give me a fancy pair of running shoes before I can run. I can't run and I would never run in a fancy pair of running shoes, and I really firmly believe that about componentry."

(ST17- Prosthetist)

Prosthetists explained that a patient should be able to attempt most activities on what they described as a 'basic leg' despite getting the impression from patients that they needed a 'running leg' to let them run. There were other activities that prosthetists saw as being an exception to this rule.

“so we do have people who have limbs for specific activities that aren't particularly suitable for everyday use, like, horse riding, kayaking, just things where the angles are all a bit weird.”

(ST01- Prosthetist)

This was linked with the patients' aspirations and an assessment by the prosthetist and other members of the MDT as to the likelihood that the patient was capable of achieving that aspiration. If the patient had tried the activity on their current limb then this was seen to reassure the prosthetist that they were serious about continuing with that activity. The patient was able to feedback about what they were finding prohibitive about their current limb. From a medical perspective the prosthetist could ask the patient for confirmation from their GP that it was medically safe for them to pursue that activity. In some cases it was reported that patients were asked to reach certain criteria before they were provided with a specific prescription.

Prosthetists talked about not making these prescriptions too specific but rather trying to cover all the activities which the patient was undertaking with their everyday limb and a spare. They talked about the maximum number of limbs an NHS patient would have being three and even that was rare. More commonly a patient would have their everyday limb and a spare and sometimes it wasn't even clinically indicated to provide them with a spare.

6.3.5.4 Prescription justification

As discussed above clinicians found it difficult to say categorically from the available literature what the 'right' thing to prescribe was and in cases where they were asked to justify their prescription choice there was a lack of unbiased research evidence. They reported that this could make it difficult to back up the prosthetic choices which they made.

Justification was raised by all prosthetists interviewed for this study, it was apparent that in providing a prescription which was considered out of the ordinary prosthetists were required

to justify that choice because of the cost implications of providing those components. Prosthetists were expected to make a clinical case for the suitability and need of that prescription for their patient to their clinical superior or directly to the prosthetic service manager. The implication of the lack of research was that this justification was difficult to achieve. On the other side of the process prosthetists needed to be able to justify to patients why they could not be provided with particular prescriptions, whether this was as a result of budgetary constraints or through lack of evidence to support using it. The result being that budgetary restraints and the lack of research evidence were confounding factors in being able to provide something that the prosthetist saw as being clinically appropriate.

Key points

1. Prosthetists often cited cost as being a factor in their prescription choices – particularly in the consideration of the prescription of high end components.
3. Across limb fitting centres there was agreement about high end components that would not be prescribed through the NHS.
2. Prosthetic prescription is not a one off judgement/decision opportunity – it is revisited regularly over time, it is also a decision which the prosthetist has the opportunity to take time over, they are not subject to time pressure.
2. While they tried their best to gauge what a patients future activity level would be it was not a major concern if they got this wrong and a change was needed.
3. In some cases patients could be prescribed additional limbs which were specific activity related. There did have to be a clinical indication of need and buy in coming from the patient that they were serious about pursuing that activity.
4. Prosthetists were able to get additional support from other members of the MDT around the suitability and practicality of prescribing different types of limbs.

6.4 Conclusion

The findings presented in this chapter indicated that prosthetists make their prescription in two stages. The first stage was the assessment which allowed them to develop an initial conceptual prosthetic prescription and, the second stage, the decision, in which they considered a patients conceptual prescription outwith the assessment appointment, considering information beyond what the patient themselves have been able to give them.

Factors which were identified as influencing the development of the conceptual prescription were the physical presentation of the stump, level of health and activity of the patient prior to amputation, their current level of activity, their goals and aspirations, patient feedback, their cognitive ability and family involvement. Prosthetists identified that they were not able to use all of these factors for each of their patients. Additionally, prosthetists varied in their assessment of the level of importance of each of these factors and it did not appear that there was one factor which all prosthetists considered to be key in each prescription decision which they made. Instead it seemed that in the assessment of each patient there would be one factor which the prosthetist identified as being key which influenced their prosthetic prescription decision above all other factors at that time.

It seemed that the prescription process could vary from case to case with three main categories of process occurring. In the first category of cases the prosthetists talked about the assessment stage as being sufficient for them to go straight to a definitive prescription. This level of certainty appeared to be linked to the level of experience of the prosthetist as well as the complexity of the case. In the next category were instances where, after the assessment process, no conceptual prescription had been made, rather, the prosthetist kept all of their options open and went on to make a decision in the next stage. The third and most common process was seen as one where by the end of the assessment prosthetists had constructed a conceptual prescription containing a small number of options that they would explore further in the decision stage

This decision stage allowed them to consider their conceptual prescription in more detail as well as to gather information outwith the patient assessment. The activities which prosthetists talked about using during this stage included negotiation and interaction with the patient, which was facilitated by the establishment of a good working relationship between the prosthetist and the patient. Further activities were; considering the financial aspects of their conceptual prescription, discussion with their peers as well as information gathering from other members of the MDT, particularly physiotherapists. They also used their own tacit and experiential knowledge and considered the available technical information, guidance and research available for the components which comprise their conceptual prescription. It could be seen that prosthetists felt that some of these activities were more valuable in their prosthetic decision, for example, prosthetists appeared to have a high level of trust in their own as well as their prosthetic peers' experiential and tacit knowledge. In a few cases prosthetists identified discussing choices with other members of the MDT, most commonly the physiotherapist and for knee prescription choices. Other less commonly used activities were

the use of trial components and lastly research literature was the least valuable and least employed as an activity in the decision stage. It was clear from the data that prosthetists would not carry out each of these activities for every prosthetic prescription they made. In some cases none would be used where in other cases a series of these activities might be undertaken. It appeared that the number of activities that prosthetists engaged in during the decision stage was dependent on the point that they felt satisfied that they could justify their prescription choice. It was evident that this concept of justification was prevalent within prosthetists working environment.

The definitive prosthetic prescription could either be the initial conceptual prosthetic prescription that the prosthetist had brought forward from the assessment stage or an amended prescription based on the outcome of the activities of the decision stage. Prosthetists saw their role as understanding the importance of each of the factors in both stages of the process and balancing the pertinent factors to make a suitable prosthetic prescription for each individual patient.

This process of decision making in prosthetic prescription is one which is repeated over time. The initial primary prescription is made shortly after amputation and repeated when indicated during the process of review of prosthetic patients. The longitudinal decision making process by prosthetists for each patient includes cycles of this assessment and decision process over what can be many years. The other aspect of decision making in prosthetics is that it is not a decision which is required to be made under time pressure. Prosthetists can be seen to have time to consider different options for prescription. A diagram illustrating a model of decision making by prosthetists derived from this data analysis can be found in Figure 20.

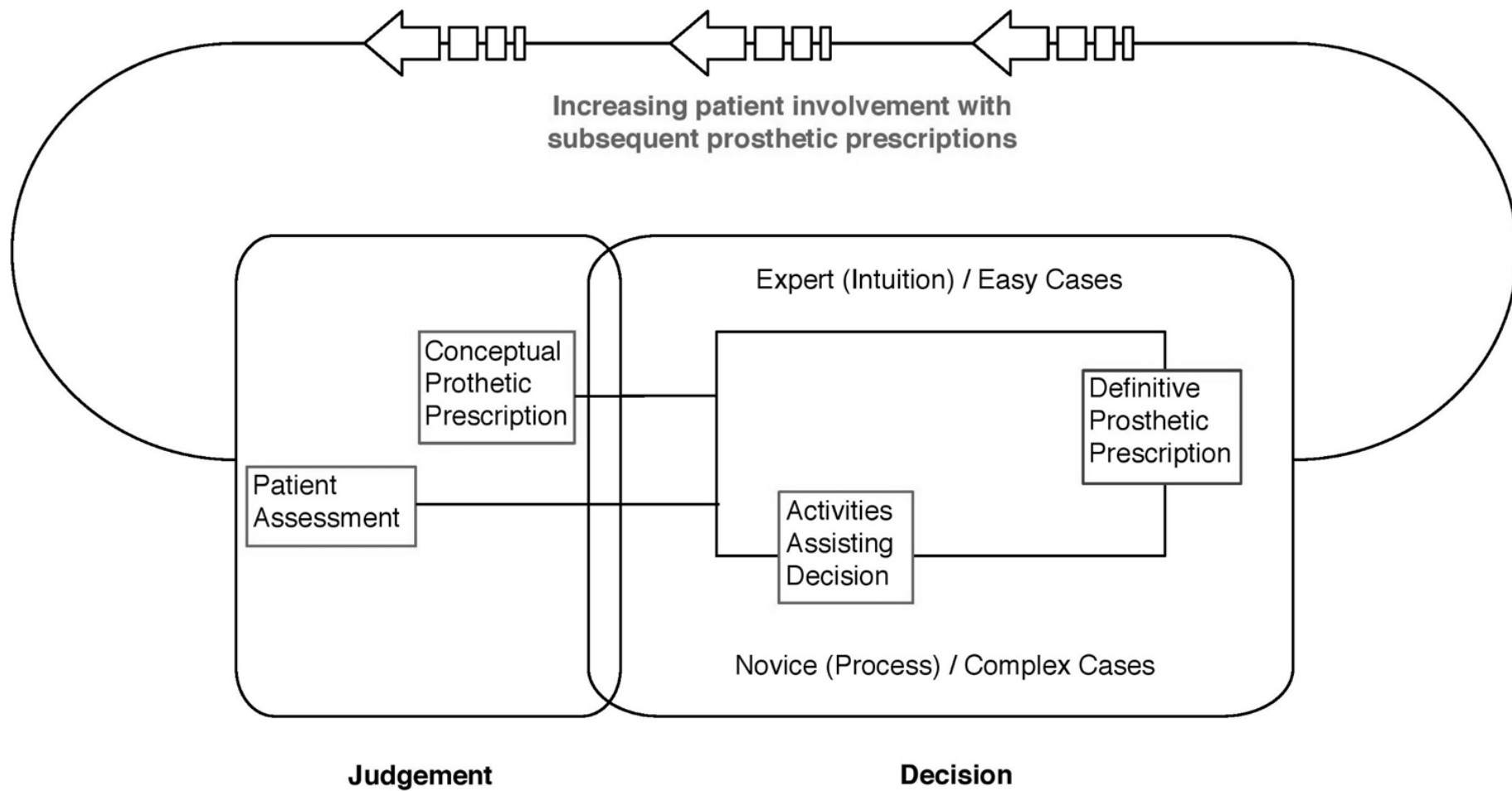


Figure 20: Model of Prosthetists' Decision Making

7 Chapter 7 - Exploring patient's experience of prosthetic care in the UK

7.1 Introduction

The results of Study 2 are based on the data collected from a sample of eleven participants with experience of traumatic limb loss. All participants who volunteered to take part were men; five being civilian amputees and six veteran amputees. This study aimed to explore three aspects of UK prosthetic care: firstly experiences of prosthetic care in both the NHS and MOD settings, secondly perceptions of involvement in prosthetic care and in particular the prosthetic prescription process and finally military veterans experiences of transition of care from the MOD to the NHS. Interviews with civilian men focussed on their involvement in prosthetic care and the prescription process, whereas the interviews with their veteran counterparts focussed on these aspects in addition to their experiences of transition of prosthetic care from the MOD to the NHS setting. This chapter begins with a brief description of each participant's story in recognition of the importance of these stories to their experience of living with limb loss and their experiences of care. The subsequent analysis of their accounts is then focussed on answering research questions 3-5:-

3. What are trauma patients' experiences of prosthetic care in the UK?
4. What are the experiences of involvement in decision making in the NHS and the MOD of traumatic civilian and service attributable amputees?
5. What are the experiences of transition of prosthetic care for those amputees moving from the MOD to the NHS?

7.1.1 Sample Demographics

While women were not excluded from participating in Study 2, there were no responses during the recruitment phase from any women with experience of traumatic limb loss. The resulting participant group was therefore made up of men only, six civilians with experience of limb loss and five participants with experience of having lost a limb or limbs as a result of an injury sustained during their time in military service. Sixty five per cent of patients suffering a traumatic amputation lose their limb between the ages of 16 to 54 years. All of the participants in this study fall into that age category so are representative age wise of the general traumatic amputee population in the UK. The split between male and female trauma amputees in the amputee population in the UK is 78% to 22% female. The sample in this study is therefore not representative of the general amputee population in the UK with respect to gender (Twiste 2013). Of the civilian men with amputations four had worked in manual industries at the time

of their accidents, another (aged 18) was about to start University when he was injured. **The remaining civilian amputee lost his limb while in the military over 30 years ago.** All amputee veteran participants were injured in accidents involving explosive devices.

7.2 Personal stories

The following accounts give a brief overview of the participants' stories, their circumstances of injury and becoming an amputee. They show a variety of ways in which traumatic amputation can occur and the differing degrees with which patients have been involved in the process of becoming an amputee. They also suggest how these experiences from injury to becoming an amputee and beyond can affect the prosthetic rehabilitation they then go on to have. These accounts therefore set the scene for the analysis of the patient data.

Frank was a 51 year old man who had a below knee amputation of the right leg 5 months prior to being interviewed. Frank's leg was amputated as a result of extensive damage to his right tibia and fibula resulting from a road traffic accident (RTA). Initially the injuries to the right lower limb were treated with the use of internal fixator pins with the hope that the bone portions would fuse and heal. After a time it was found that the internal fixators were not having the desired effect, additionally, as a result of the extent of the damage to the right lower limb there was a leg length discrepancy of three and a half inches between the left and right leg. Frank reported that treatment options at that stage were to apply external fixators (Ilizarov cage) to support the damaged bones and to increase the bone length over a period of time or to undergo a below knee amputation on the damaged limb. Frank initially decided to have the Ilizarov cage fitted but after only having had it for a few days decided that he would prefer to have the leg amputated. He reported that this was in part due to the uncertainty of the success of the Ilizarov cage after a projected 18 months of having to wear it and in part due to the difficulty of coping with wearing the cage in his home environment. Frank said that he was given the choice to go through the process of having the limb salvage procedure (Ilizarov cage) or to have the amputation. He reported feeling involved in the decision to amputate as he was given the choice between the two treatment options. As a result six months after the initial trauma to the limb the amputation was carried out and one month after that he was admitted to hospital for physiotherapy and prosthetic limb fitting and rehabilitation. In addition to the damage below the right knee Frank reported that there is also significant remaining damage to the right knee, which was also under orthopaedic review.

John was 41 years old and working as a manual labourer when he fell off a roof resulting in severe compression injuries to the bones of the foot and ankles of both legs. He was

taken straight into surgery after the accident and the bones in the left foot and ankle were stabilised with the use of internal rods and pins. The right leg was more severely damaged and had to be protected with a cast after reconstruction. Over a period of time the cast was removed and replaced with bandages and John was able to walk firstly on crutches then without them. After a time he felt that the left side was throbbing intermittently, this got worse to the point where it was continually throbbing. It was found that there was an infection in the bones of the left foot and ankle, in order to treat this all pins and rods had to be removed and the leg once again put in a cast with a window through which the infection could be treated. This infection persisted for three months and John had to be fitted with a central line to administer antibiotics. At this stage a relative thought that they should get a second opinion as they knew of a cage that could be fitted which might be able to help. John's surgeon was willing and he was fitted with an Ilizarov cage. He wore the cage for around 18 months during which there was constant aching and discomfort. At this stage he made the decision to have the leg amputated below the knee. After he had made the decision to have the amputation John felt that the surgeon no longer had any interest in him. The amputation was carried out shortly after that. John now has a prosthetic limb on the left side and an ankle foot orthosis on the right side to stabilise the ankle joint to reduce pain. John talked about there being discussion around having an ankle fusion carried out on the right ankle but he had fears that that could result in further infections and the loss of that leg too. John talked about the amputation in a positive way, even saying that he wished he'd had it done sooner. At the same time he reported being glad that he tried the cage and had no regrets about trying it. John spoke about it being strange that he had lost the left leg as it was the right leg which had been more damaged at the time of the original accident.

Gavin lost his limb as a result of an industrial accident in which his toes were severed from his foot just behind the steel toecaps of his boots. He was taken to his local emergency department where initial surgery was carried out to clean the wound. From injury to amputation was a long process during which Gavin had a number of instances of contracting MRSA and problems relating to cleanliness in hospitals, infection and poor quality of care. Shortly after the accident attempts were made to reconstruct the foot, this was followed shortly by an infection which required the wires which were designed to help stabilise the foot having to be removed. There followed a period of a year after the accident during which time Gavin contracted a number of infections and underwent further surgeries and attempts to salvage his foot. He reported that he was given two options at that stage, to have the foot amputated at the ankle or to have a standard below knee amputation. He chose the below knee option as the surgeon had told him that he would never be able to walk properly with an amputation

at the ankle. Since the amputation which was carried out four years ago Gavin has had great difficulty getting a prosthetic limb that he can walk with.

David lost his right leg below the knee when he stood on an antipersonnel mine while serving in the Falkland Islands. At the time of the accident only his foot was lost but due to the suboptimal length of the stump further revision surgery was carried out at a later date to shorten the stump slightly. Prior to the accident David was a physical training instructor in the army and he continued with this job after amputation, as such he has been a very active limb wearer over time. Recently, pain in the stump resulting from wasting of the stump over time which has caused nerves to be impinged. This has meant that David is now only able to wear his prosthetic limb for 15-20 minutes at a time. At the time of his accident prosthetic care for military personnel was still being provided through the NHS. This meant that when he got back to the UK around two months after the accident he received prosthetic rehabilitation through a limb fitting centre in Putney where he was based at that time. Subsequently he received prosthetic care in Cyprus, Belfast, London and in Edinburgh while remaining in the Armed Forces. When he was stationed in Edinburgh he received prosthetic care from the same hospital for 13 years. When he was discharged David relocated within Scotland and as a result from that point he has received his prosthetic care from another limb fitting centre. David talked about the issues he had with pain in the stump prior to the revision surgery, despite this he talked about having coped well with his prostheses over the years and not feeling held back from achieving what he wanted to achieve. Only within the last 2 years has the pain caused by changes in the stump and osteoarthritis in the knee of his sound limb prevented him from doing everything he wants.

Ted lost his limb 13 years ago as the result of an industrial accident during which he sustained massive injuries from his knee down to and including his ankle. He was told that they could try and save the limb but that it could take a period of years of reconstruction and they 'couldn't guarantee it was going to work'. He had experienced someone he knew going through a similar process over a period of five years at which point the limb had to be amputated. On the night of the accident he was taken into surgery to begin reconstructing the limb at which point the surgeons realised the full extent of the injuries and therefore no reconstruction was carried out at that stage. The next day they spoke to him about what they had found when they had taken him into surgery and he was told that they could give him 24 hours to think about his options. Ted decided right then to have the limb amputated. Although he had decided to have the amputation and knew that it had happened it was only when the bandages were removed two weeks after the amputation did he say he fully felt a realisation

that he no longer had that limb. At that stage Ted was self-employed and as a result it was important for him to be able to get back to work from a financial point of view. He had no other injuries as a result of the accident, he moved quickly to prosthetic rehabilitation and gave up on his physiotherapy because he felt he was away ahead of that. His first three years as an amputee were trouble free but since then he described having had continuous problems with the limb which make it uncomfortable to wear and in particular when he is riding his motorbike.

Sam lost his right leg below the knee when he was involved in an RTA at the age of 18.

His limb was traumatically amputated on impact at the time of the accident. He was taken to a local hospital where his condition was stabilised as he had lost so much blood. He was then airlifted to a larger hospital for further treatment. As a result of the accident he required surgery to 'tidy' up the stump. Skin grafts were taken from the severed limb to graft to the damaged knee and thigh section of the affected limb. He spent just under a month as an inpatient during which he caught MRSA which slowed the healing process slightly. Two and a half months after the accident Sam was fitted with his first prosthetic limb. During the first few weeks of prosthetic limb wearing he had some issues due to the breakdown of the graft and scar tissue on the stump. He attended the limb fitting centre as an outpatient and was first seen by the prosthetist which he has had ever since the time of his accident three and a half years ago. He also had physiotherapy at a more local hospital during the beginning of his prosthetic rehabilitation. More recently Sam has experienced severe back pain for which his insurance case manager is trying to access private physiotherapy. Since early on in his prosthetic rehabilitation Sam has been able to get back to his extreme cycling and since has been involved in a wide variety of activities including snowboarding.

Chris is a veteran who served in Afghanistan; while he was there in 2009 an improvised explosive device (IED) was detonated underneath the vehicle he was travelling in.

As a result of this explosion Chris sustained crush injuries to his ankle and the side of his foot was 'split open'. Once stabilised in the closest field hospital he was flown by Medivac back to the UK for further treatment. While hospitalised the wound became infected and more and more tissue became affected. He also underwent removal of some of the calf muscle and a skin graft was applied to cover the missing tissue. Chris was in hospital for ten and a half weeks during this process and while the wounds healed. He then spent time at Headley Court having physiotherapy on the foot and ankle but he felt that it wasn't getting any better and that in fact, the pain was getting worse. This continued for around two years when he came to the decision that he wanted to have the limb amputated. Around the time that Chris was at Headley Court there were a number of other soldiers with the same sort of injuries who had had an amputation

and he could see how well they had got on and that they had made much better progress than he had. He had a below knee amputation and received prosthetic care at Headley Court until he was discharged from the Army three years after he was injured.

Colin is an Army veteran who involved in an explosion in 2003 while he served in Iraq.

He was flown back to the UK shortly after he was injured and treated at Selly Oak in Birmingham. During the explosion he had sustained injuries to the foot, ankle and had shattered the tibia and fibula. Surgeons at Selly Oak assessed him and told him 'we're going to need to do an amputation' suggesting that keeping the leg would cause problems. Colin says that he did not have to decide to have the amputation and that he was happy to follow the opinion of the professionals on the best course of action. So less than a week after the accident he had the limb amputated below the knee. After the amputation he spent three months at Selly Oak and receiving physiotherapy at the rehabilitation centre there. After he was discharged from Selly Oak he returned home to Scotland and was provided with his first prosthetic limb from an NHS limb fitting centre around four months after his accident. He spent periods of time at Headley Court after this for his rehabilitation and enjoyed the periods he spent there as he felt quite isolated when he was at home. He began playing football and running with his prosthesis a few months later, something he had loved doing before the accident. He has always received his prosthetic care through the same prosthetic centre. He was discharged from the Army around 4 years after he was injured, he was given the opportunity to remain in the Army in an office position but he asked to be discharged as he was unable to do the things he had joined the Army for.

Rory lost both his legs when he was involved in an explosion while he served as a soldier in Afghanistan 5 years ago.

The detonation of an IED while he was on patrol caused him to lose his left leg below the knee and the right leg above the knee. The left leg was 'blown off' at the time of the explosion whereas the right leg was still attached but was severely damaged. He was airlifted to the hospital at Camp Bastion. When he woke up the right leg had been amputated. Around 36 hours after the explosion Rory had been transferred back to the UK to Selly Oak Hospital where he was an inpatient for four to five weeks. Since his injuries Rory has had 27 surgeries including numerous skin grafts and contracted MRSA seven times. He said that 'Infections, obviously in these bombs you've got rat poison, you've got...you name it, they put it in it, so it's not losing a limb, it's the infection'. Only after all of these surgeries could the injury sites heal and for Rory to be free of infection. After being discharged from Selly Oak he spent a week at home over Christmas and New Year before attending Headley Court for rehabilitation. Full time rehabilitation at Headley Court consisted

of blocks of four weeks at Headley Court followed by four weeks at home; this process was then repeated throughout the rehabilitation process. This lasted for two years after which he was only attending Headley Court as an outpatient for his prosthetic care. Three years after he had been injured Rory was discharged from the Army on medical grounds. This was a decision that he said he accepted straight away; he did not want to be in the Army anymore. It was not a decision he was happy with but after he was injured he felt that being medically discharged was realistically what would happen at some point and if he wasn't able to do what he had joined the army to do then what was the point in him staying? After discharge his prosthetic care was taken over by the NHS at the limb fitting centre closest to his home after a time he asked to be transferred to a designated veteran prosthetic centre for his care.

Jack was a serving as a Marine in Afghanistan when he was blown up by a tripwire IED which resulted in 27 separate injuries. Once his condition had been stabilised Jack was transferred back to the UK where he spent his first two weeks in hospital in a coma due to the extent of his injuries. After he woke up doctors gave him the option of having his limb amputated below the knee or having his lower limb put into an Ilizarov frame to support the tibia and fibula and grow the missing length in these bones caused by the injuries. The doctors were confident that they could achieve this with the frame in 18 months. Jack said he wasn't 'in a rush to start chopping part of my body off' so he agreed to go ahead with the Ilizarov frame. After a year of wearing the frame Jack reported that he had so much nerve damage that he could not feel his foot and the ankle was almost fused together, he was unable to wiggle his toes and no longer had protective sensation in the foot. During this period he was based at Headley Court for rehabilitation and on a daily basis could see soldiers who had undergone amputations getting better and he said that he almost felt jealous of their mobility and began to feel that amputation may be the best option for him. Around 18 months after his initial injury Jack decided to have the leg amputated just below the knee for a better quality of life and to get back his mobility. After the amputation he continued to have rehabilitation at Headley Court and spent the rest of his time at home. During the first year of amputation he suffered a number of setbacks which slowed his progress as a result of other injuries he had sustained. He also spoke about some of these setbacks resulting from him wanting to push really hard with his rehabilitation because of his personality and desire to get better. These setback included surgeries for infections of the stump. One of the other factors was that he has severe foot drop of the other leg as a result of nerve damage, a break in the amputated limb which causes pain and various other injuries. All of these impacted on his rehabilitation. Now he is a very keen runner who has run a number of 10k's and is attempting to become the world's fastest single leg amputee at 10k, and also participates in a number of other activities.

Around 18 months after his amputation Jack was discharged from the Services. He saw this as being partly his decision and partly for medical reasons, he felt that had he stayed there would not have been a career for him because of his injuries and financially he felt that he would be better off out of the Services. He felt that he could have stayed if he had wanted and he wasn't pushed.

Douglas was serving as a Paratrooper in Afghanistan in 2011 when he stepped on an IED and both of his legs were blown off. Following the explosion he was flown by helicopter to the hospital in Camp Bastion, due to his injuries he was sedated and two days later woke up in hospital in Birmingham. At this stage they spoke to him about the surgery which was required to clean up the damage to his residual limbs which included reducing the length of the right stump as the limb had been blown off right through the knee joint which would make prosthetic fitting very difficult. He had this revision surgery only a few days after the explosion. After this Douglas underwent numerous operations to treat various injuries sustained during the explosion including massive reconstructive surgeries to the thigh and other soft tissue sites of the thighs and trunk. He spoke about being thankful for the surgeries as they gave him an opportunity to sleep which he was struggling to do on his own as a result of memories from the explosion making him scared to sleep. This process of surgeries and grafting and healing meant that he remained in hospital in Birmingham for eleven weeks after which he spent two weeks at home before starting his rehabilitation at Headley Court. Two days after he arrived at Headley Court he was fitted with check sockets. By this stage he felt ready to be fitted with his limbs and due to his other injuries his stumps had had a longer period of time to heal before prosthetic fitting. After arriving at Headley Court he 'binned his wheelchair' and decided that he would walk everywhere and as soon as he had legs and could walk he did. He reported that his mind set developed during his training played a large role in his recovery. Seeing a friend die in the process of saving him made him want to get on with his life. He reported being very focussed. Douglas felt that the environment and competition at Headley Court motivated everybody in their rehabilitation. Very early on the decision was made that Douglas would be medically discharged from the Armed Forces, He was told 'we don't keep wounded guys on anymore' and that there was no job for him in the military. At that stage Douglas talks about having been willing to do anything to stay. He then spoke about how over time he came to accept the decision and after a smooth transition it was ok because when it happened he felt ready.

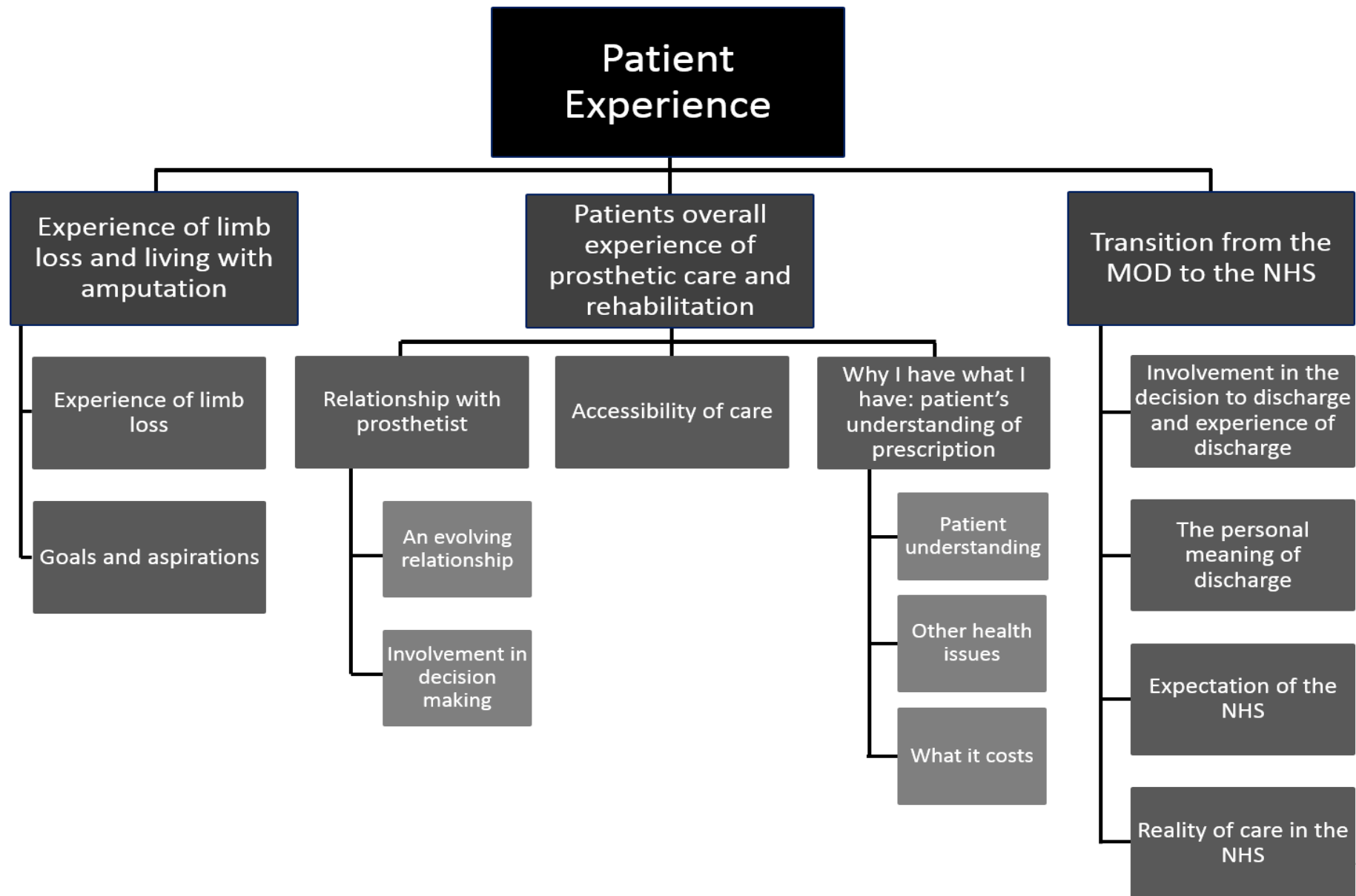


Figure 21: Data analysis matrix: Patient Experience

7.3 Analysis

Data collected from participants during this study were organised into three main categories: 'Experience of limb loss and living with amputation', 'Patients' overall experience of prosthetic care and rehabilitation', and 'Transition from the MOD to NHS'. Nine themes were then identified within these three broad categories (see Figure 21).

Experience of limb loss and living with amputation is the category that contains data that arose primarily from asking the men to talk about the situation which led to them being an amputee. It became clear from their accounts that these stories were not separate but rather an integral part of understanding their subsequent experiences of prosthetic care and rehabilitation. Data from these stories were considered in two themes; 'Experience of Limb Loss' and 'Goals and Aspirations'. These themes describe the wide range of circumstances and processes which resulted in their amputation and how these men handled those situations as well as looking at what they can and hope to, achieve in the future as an amputee. Both of the themes in this category contain comparisons between the experiences of limb loss, goals and aspirations, and how these relate to care experiences for men who received treatment in the MOD and NHS.

The second main category related to the men's overall experience of prosthetic care and rehabilitation. Three themes were identified: 'Relationship with the Prosthetist'; 'Accessibility to Care'; and 'Why I have what I have: patient's understanding of prescription'. 'Relationship with the Prosthetist' considered the important aspects which they felt contributed to the relationship or lack thereof, what aspects helped to create a good relationship, and what could be improved upon. It also explored the form that this relationship took for different men and at different stages of their rehabilitation and how the relationship influenced the men's involvement in decision making. "Organisation and Accessibility to my Prosthetic Care" looks at how these men view the organisation of prosthetic care, how they can access that care and the ease of doing it. It also explores situations where they perceive the organisation to have an impact on the care they receive and their experience of that care. The final theme in this category, "Why I have what I have: patient's understanding of prescription" explores their understanding and reflections on the prosthetic limbs which they have been prescribed. It also explores their views on, reasoning and understanding behind what they have been provided with.

The final category relates to transition of care from the MOD to the NHS and contains four themes, "The Personal Meaning of Discharge", "Experience of Discharge", "Expectations of the NHS" and "Reality of Care" these in turn analyse the story of the

experiences which injured military personnel go through from the time of their injury through discharge and back into civilian life.

7.3.1 Experience of limb loss and living with amputation

7.3.1.1 *Experience of limb loss*

Each interview began by me asking the men to describe when and how they had lost their limbs. All appeared to speak openly about the circumstances of their amputation. The men in this group could be divided into three groups, those who had no part to play in the decision to amputate, those who made the decision to have an amputation before or after a period of limb salvage and those who felt that the choice between limb salvage and amputation had been taken away from them. Each of these groups consisted of both civilians and veterans.

Those who played no part in the decision to amputate were those men who had suffered a traumatic or primary amputations. Sam, Douglas and Rory talked about the experiences they had of this route to amputation.

“...it took me about a week to ten days to even realise that my leg was gone, and my mum says... like, I spoke to my mum about it and she says basically I got an itchy foot and went to itch it and I didn't have a foot there, and so I like questioned – my dad and my brother were sitting with me and they explained to me what had happened, and I didn't really believe them, wasn't really sure and I flagged down a nurse that was walking past, and I said 'do I have a right foot?' and she said 'no, no you don't, you were hit by a car' and she told me all the story then. “

(Sam, civilian participant)

“I had to...I was actually isolated when it happened, so I had to treat myself, so I understood...I was totally aware and awake and not in any pain. It was quite strange but...yeah...A level...we're all very well trained in traumatic first aid, basically point of wound and stop bleeding. We're very...the use of tourniquets and you used to use this stuff called HemCon and other, kind of, clotting substances to stop it, but, yeah, it was...but I was able to apply two tourniquets on to my legs and then I just, kind of, curled up in a ball while I elevated the bleed and waited for one of the guys to get to me.

(Douglas, amputee veteran)

“The left below was completely off, the right one was...it looked like it had been rolled over by a steamroller, it was all mangled, mashed, pretty much, so I’ve had 27 operations, I’ve had MRSA seven times and I’ve had numerous skin grafts, etcetera...No, no, literally I was stuck on the back of a Chinook, got back to Camp Bastian hospital and when I woke up, both legs were gone.”

(Rory, amputee veteran)

For those who were able to be involved in the decision to amputate, this happened at different stages after their injury. Some like Ted talked about making the decision to amputate within a week of his accident. Others decided only a short time after the process of limb salvage had begun while the remainder went through up to three years of limb salvage before deciding to have an amputation. Each of these men talked about what had influenced their decision to them make their choice have an amputation. The largest influence in this decision could be attributed to these men considering the experience of others in a similar situation. For some this was having seen others who had already had an amputation getting on better in their rehabilitation than they were while undergoing limb salvage. Another had previously experienced a friend going through a protracted period of limb salvage and ultimately amputation. He reported that he did not want to go through that same experience so wanted to have the limb amputated as soon as possible. Finally, one man spoke about the pain and frustration of the limb salvage process pushing him towards making the decision to have an amputation. The men in this group felt key in instigating the process of having an amputation.

“I lost it 12 year ago in March this year. I was at my work and I got dragged into a wood chipper, there was no damage to my foot, it was between my foot and my knee all the damage took place. They tried to save it, it was just no, no I just says to them to... they said they could’ve saved it but it was going to take years and years of rebuilding and they couldn’t guarantee it was going to work, so I’d seen somebody going through it all before, they’d went for about five year and they ended up losing their leg after five year and I just said to them, just take it off.”

(Ted, civilian amputee)

“And in the end it was just a case of, I was [inaudible 0.02.29] guys who, other guys, there was a good soldier who had been injured who were amputees, were, kind of, running around doing all these things that I couldn't do and I almost became jealous of their mobility that those guys had and then in the end I just decided amputation might be the best option. “

(Jack, veteran amputee)

“I'd seen other people getting on, having the amputations, cause there was a few of us around the same time with the same injuries. They had had an amputation and they were up and gone.”

(Chris, veteran amputee)

The final group are those who felt that while they were party to the decision making process to amputate they ultimately felt that circumstances meant that the amputation decision had been taken away from them. In Gavin's case the amputation resulted from quite an extended period of salvage like those in the group above but in his case the decision was made after a number of hospital errors resulting in multiple infections and long periods of pain which meant that the only remaining option was to undergo amputation.

“But then the doctor, he came up and he says, we're going to need to do an amputation because it would give me years, but if I kept it the two bones would be rubbing together like that...I shattered the tibia and fibula completely and then gangrene started setting in so I was like a big lump in my throat and was like, all right, you're the professionals so you know what you're doing.”

(Colin, amputee veteran)

“I met a [Doctors name]who's the older brother of the very first doctor I spoke to and he's the consultant up there, really liked the guy and you got on great with the bloke...he turned round and he's to me, he says, right, I'm going to give you two options. Option one, amputation. The amputation starts from

the front of your ankle to the forward bit of your foot, but you'll never, ever be able to walk properly, ever. Not even with a prosthetic... Option two, is going to be 150 millimetres below the knee, standard amputation.

(Gavin, civilian amputee)

7.3.1.1.1 Feelings after amputation

Different groups reported having different feelings about their amputations. The first group talked more about how they came to terms with the loss of their limb and how there was the need for a period of adjustment in the beginning. The overall feeling from them was that it was just something that had happened and they realised quite quickly that they just had to deal with it and attributed their successes as an amputee relating to a positive outlook from an early stage.

Those in the group who had been involved in the decision to amputate spoke about having more positive feelings and feeling of relief after their amputations and often spoke about feeling relief after having experienced the process of limb salvage. They were also able to identify the benefits of having undergone amputation.

"A lot better than what I ever thought it would've been, you know, before... I sort of said to friends before 'if I lose my legs, don't worry, just let me bleed out and carry on' and now that I've seen people and, you know, I've gone through the whole thing myself, it's really not that bad, you know, it's... it's nowhere near as daunting as what I thought it was going to be."

(Chris, veteran amputee)

"I wish I'd got my leg off sooner than I did, know what I mean, instead of putting that frame on"

(John, civilian amputee)

Although he had not been able to take part in the decision to have an amputation having experienced limb salvage over a period of years Gavin talked about the relief he had felt after amputation.

“Great. Absolutely brilliant. I thought to myself, God, what...it was just...it was like, you know, somebody’s put a big weight on top of your shoulders and taken it off you, you know.”

(Gavin, civilian amputee)

7.3.1.1.2 Military mind-set in amputation

A particular mind set was apparent in the veteran amputees. This mind set and the effect that it had on men’s feelings on their amputation was apparent in a number of men who had experienced rehabilitation at Headley Court. They spoke about the benefits that rehabilitating with so many others in a similar position to themselves had had on their feelings towards their amputation. As described above, this could be seen to influence the decision to undergo amputation. Others spoke about this shared rehabilitation providing a camaraderie and competitiveness which inspired them to push harder to see what they could achieve as amputees and how they used that to boost each other. The positive attitude instilled by the military was also spoken about by two of the civilians who has served in the military in the past when they discussed how the training they had received while serving had influenced how they had viewed limb loss.

7.3.1.1.3 Coping with limb loss

Among both civilian and veterans the use of humour as a coping strategy was used by numerous participants. In the previous section Frank was quoted as using quite gruesome and matter of fact language to talk about the decision to have an amputation that he had made while at the same time punctuating his language with laughter to perhaps trivialise a very traumatic situation. Chris did a similar thing when he spoke about posting a before and after amputation shot on Facebook with the caption ‘now you see it/now you don’t’, despite having said prior to his injury that if he lost his legs colleagues should just to leave him to bleed out, he used the humour to highlight how his feeling towards amputation have changed now having gone through the process himself to the point where he can joke about it. Ted spoke about using his stump in practical jokes whereas Colin explicitly talked about using humour as a coping strategy after his amputation.

“I just make jokes about it. I mean if you don’t laugh you cry, you know what I mean”

Colin (veteran amputee)

Douglas also talked about the use of 'black humour' at Headley Court and the positive effect it has during rehabilitation.

"And we've got this horrible, horrible sick sense of humour, the black humour...even the American army just don't . . . Don't click with you, so that really...humour just gets everybody though, like, big time."

Douglas (veteran amputee)

Key points

1. There are three levels of involvement in decision making in amputation; (i) no involvement or awareness at the time of the amputation, (ii) active participation in the decision to amputate and (iii) awareness but inability to take part in the decision to amputate.
2. Those undergoing limb salvage saw value in seeing others go through the process of amputation and improve as well as men who had had an amputation valuing seeing men doing well further down the rehabilitation process.
3. Mode of amputation and the ability to take part in the decision to amputate seems to affect the process of adjusting to becoming an amputee.

7.3.1.2 Goals and aspirations

7.3.1.2.1 Employment

The inability to return to the jobs they were trained to do prior to their amputations was apparent for both the veteran and amputee participants. For the majority of the civilian men their jobs were manually based and amputation meant that they had either been unable to return to those jobs and were therefore not working or they had had to completely change the type of work they did in order to return to work, as in the case of Gavin. All amputee veterans who had been injured in recent conflict were unable to return to the service jobs they were trained to do, in the majority of those cases this meant that there was no longer a place for them in the services leaving them with the prospect of retraining and beginning a totally different working life as a civilian post discharge. For those who were given the opportunity to remain in the services, like Colin, this would have meant completely changing from what he had joined the Army to do. Ted felt that his amputation meant that he could no longer do the job he had done previously due to the nature of his work combined with the problems he experienced prosthetically. He felt that even if he did something different job wise he would still struggle to get and keep work with the problems he has with his prosthesis.

"I never looked for work. But now who's going to take me on, that's the way it is, even in something else, you know, especially with all the bother I get."

(Ted, civilian amputee)

7.3.1.2.2 Activity

Ted talked about other things which having a prosthetic limb made difficult, in particular he found kneeling hard due to the way the socket was cut at the back which made it hard for him to achieve his hobbies of motorbike riding and shooting. He spoke about wanting more movement in his prosthetic foot and being unable to get a foot like this though the NHS. As a result he felt that he was being held back from being able to achieve more. From the perspective of talking about what he had been able to achieve since becoming an amputee he spoke about having told his prosthetist not long after he had become an amputee that he had the ambition of wanting to walk the West Highland Way which he achieved within a year of undergoing his amputation. Both David and Ted felt that they were now able to achieve less as amputees than they had been able to in the past. David attributed this to how active he had been after amputation and how hard he had been on both his amputated and contralateral limbs. Ted saw his restrictions in activity as attributable to ongoing issues with his prosthesis.

The remainder of the men talked about their goals and aspirations as things that they were still in the process of trying to achieve. Some talked about their goals as being simple things based around getting back to their day to day lives, for example Gavin, Frank and Rory talked about their goals in simple terms.

"I basically want to be able to walk fairly normal without crutches constantly."

(Frank, civilian amputee)

"But I mean certainly moving about with ease, you know, it's just stuff like that... Just day-to-day stuff, without having to, oh my God, I can't move, or, I can't fit my leg."

(Gavin, civilian amputee)

"Not really...well, I'd like to play football with my son or go on a climbing frame. For me it's small things, it's not the big things. I can live without running, I don't run, I can live with that."

(Rory, veteran amputee)

Both Gavin and Frank spoke about further goals but in a way which seemed to indicate that they were not goals that they felt they would ever be able to achieve from the point they were at in their rehabilitation when I interviewed them.

"If I want to be really, really, really keen, I says, I wouldn't mind going hillwalking like I used to. Or doing something like that. But I know it'll never happen. One, I'll probably collapse halfway up a ... mountainside anyway. Two, I would probably...wouldn't survive the first hundred yards and fall flat on my face. So realistically, that's just cobblers."

(Gavin, civilian amputee)

Rory had set himself an important goal shortly after his double amputation which he was able to achieve.

"Yeah, to walk down the aisle, because I was getting married that year, so, October, so I had ten months to learn to walk, pretty much."

(Rory, veteran amputee)

Across both civilian and veteran groups there was a wide spread feeling of not feeling held back as an amputee with a number of them having done or being in the process of working towards huge goals. Sam saw his goals and aspirations as a continuation of those which he had had prior to his amputation. Adventure cycling was a way of life for him before amputation so he simply did not see not cycling at that level as an option, he also wanted to continue to try new things.

"And I read a little bit in that about an above the knee amputee who could still snowboard and I was like 'right, if an above the knee amputee can still snowboard and looking at me how I'm doing back on the bike and everything like that already, then I shouldn't have any problems'"

(Sam, Civilian amputee)

Within the group of men who had suffered limb loss while in the Services there were a number that were aiming for ambitious goals, Douglas had set his sights on becoming a

member of the GB Paralympic rowing team, Jack was aiming to become the fastest man with one leg over 10km and so far had run three half marathons and a number of 10k's as an amputee.

7.3.1.2.3 Confounding factors

Two of the men identified that it was not the amputation itself that they felt held them back from reaching their goals but instead further injuries they had sustained during their accidents. Frank identified that while he felt that he could improve with the prosthesis and would over time, he felt that it was the injury to his knee, sustained during the accident which led to his limb loss, which was proving the biggest barrier to him achieving improved mobility. Similarly John talked about other injuries, including severe joint pain, restricting his mobility. He identified this as being what prevented him from getting back to work, even in a different job to the one he had prior to his accident.

Key points

1. Employment was a big issue. In this group there was only one case where the participant had managed to return to the same job they had had prior to amputation. Many had lost their jobs as a result and were yet to negotiate what form work in the future would be. For some they did not see returning to work as an amputee as an option.
2. Some men felt that amputation had no effect on their goals and aspirations while others had had to reassess them and identify new goals.
3. The men all had an understanding of why they were unable to achieve their goals, co-morbidity, pain, further injury and deterioration over time.

7.3.2 Patients' overall experience of prosthetic care and rehabilitation

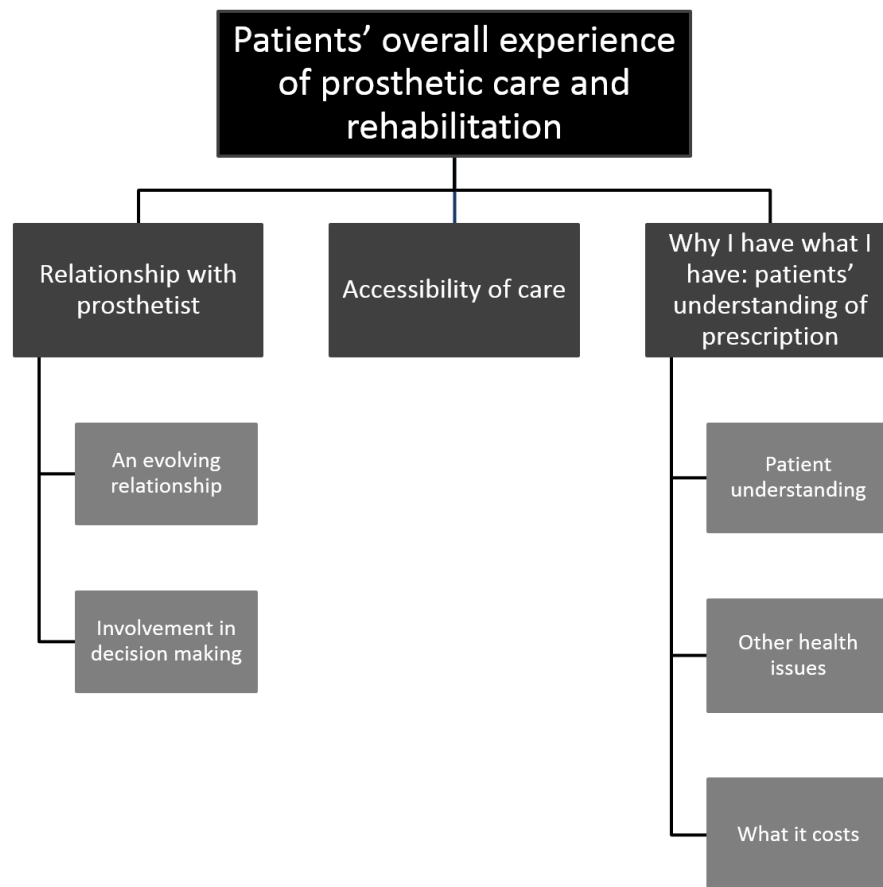


Figure 22: Patients' overall experience of prosthetic care and rehabilitation theme structure

This section of the data relates to the research questions posed to patients about their feelings of involvement in their prosthetic care and their experiences of their prosthetic care in a more general sense. There are then three themes which incorporate the findings from that section of the patient data; (i) Relationship with Prosthetist (ii) Organisation and Accessibility to My Care and (iii) Why I Have What I Have: Patients' Understanding of Prescription.

Each of the themes under this heading represent data gathered from civilian and veteran amputee populations, therefore there is comparison of the experiences between settings.

7.3.2.1 *Relationship with prosthetist*

7.3.2.1.1 An evolving relationship

All of the men undergoing amputation as civilians spoke about the continuity of care they had received in the NHS, for some this was seen as positive while for others it was

negative. Frank and Sam were relatively new amputees and both had only had one prosthetist since their amputation. David who had been an amputee for over 30 years had seen a number of prosthetists at different centres, however, his prosthetist had not changed in the time that he had attended his current limb fitting centre. They reported that this allowed them to get to know their prosthetist, to trust what they did and to build up a rapport with them. The particular benefit that John identified with continuity was that it meant that he did not have to keep explaining his full story over and over again as he had had to do for other health care professionals. Seeing the same prosthetist at every appointment made him feel that his prosthetist knew where he was with his rehabilitation and was able to understand what John's issues were with the prosthesis and how to fix that, so John was able to trust his prosthetist to address any issues.

Sam spoke about the instant rapport that he had with his prosthetist through shared interests and then went on to talk about how this continued into a relationship where there was clear exchange of information on both his part and his prosthetists as well as an understanding between the two of them on what he wanted to achieve and the prosthetist working hard to enable him to achieve it. Frank also spoke about forming a rapport with his prosthetist through the sharing of common interests, even at only six months post amputation he spoke in a relaxed way about his relationship with his prosthetist and the ease of accessing his prosthetic care.

"I phoned them up and said my leg was getting quite slack so they just gave me an appointment to come in and get it recast. I'm quite friendly with the guy that does my legs up here, he's a biker as well, so I was due to go to Dundee on the Friday to see the surgeon and I was supposed to be back on Monday to see the guy that makes the legs and I met him in the bike shop in Kirkcaldy and I says 'I'm up there on Friday and I'm back on Monday' he says 'just phone me direct in the office' so they just changed it and done them both on the same day, so that was really handy."

(Frank, civilian amputee)

The accounts of continuity of prosthetic care from the men who had received prosthetic rehabilitation at Headley Court varied. Douglas reported that for the three years he was at Headley Court he had the same prosthetist who was able to accommodate an appointment at short notice. In some cases this would involve the prosthetist dealing with more than one patient at a time while different aspects of the issue were being dealt with and would go back and forth between the men. Conversely Chris and Rory reported

receiving their care from a number of prosthetists during their time at Headley Court, for Chris this was the result of three prosthetists in a row going on maternity leave and for Rory it was because he was under the care of a number of prosthetists who only worked at Headley Court for short periods of time. Rory found this process of changing prosthetists so frequently frustrating as he felt he was constantly repeating himself before he could move forward, similar to how John had felt with other healthcare professionals.

Gavin's experience of the continuity of prosthetic care that he had received stood out because he viewed this as a negative. He discussed throughout the interview the strain on the relationship between himself and the prosthetist he had attended for around the first two years as an amputee. Almost from the beginning he talked about not trusting his prosthetist and the difficulties they had in providing him with a prosthetic limb which fitted appropriately. His prosthetist was only changed after a large number of ill-fitting limbs and a breakdown in communication with Gavin which resulted in him making a formal complaint. Gavin reported that since changing his prosthetist there has been an improvement in the prosthetic limb he was provided with and the communication between himself and his new prosthetist. The feeling of not being listened to or given sufficient information by his previous prosthetist was one of the main aspects of breakdown that Gavin spoke about. Ted also spoke about feeling like he wasn't being listened to by his prosthetist and how this could be frustrating telling them the same thing over and over again. Like Douglas's experience at Headley Court, Ted reported that there were times that during an appointment his prosthetist would also be dealing with up to three other patients at the same time. He spoke about feeling that this made it more difficult for the prosthetist to take in and act on what he was saying. His perception was that there was an issue in the prosthetist relaying the information he was giving them on to the technician and that this could be solved by him being able to discuss his limb with the technician directly.

Only Gavin really identified having a serious issue with good continuity of prosthetic care, this was associated with the quality of care he was receiving and in a situation where he was only able to see that prosthetist it took a complaint to change that situation. John and Rory highlighted difficulties associated with lack of continuity of care, in that that they would constantly have to repeat their story in order to move forward with their care. Positivity towards continuity of prosthetic care was seen from almost all other men who were interviewed as a way of strengthening the patient/clinicians relationship.

Key points

1. In the majority of cases continuity of care was considered to be an important aspect in forming a relationship with their prosthetist.
2. Continuity was perceived to improve the quality of care they received in most cases.
3. Rapport was quickly established between men and their prosthetist where they had shared interests.

7.3.2.1.2 Patients involvement in decision making

This theme reflected on the ways that patients felt they were involved in their prosthetic care and the prescription process. It explores how they talked about their interactions with their prosthetists during this process.

Men spoke about their involvement in the process in different ways. Each of the men talked about the process of meeting with their prosthetist throughout their prosthetic rehabilitation and about being asked what they would like to be able to achieve as an amputee. Most of the men felt that they were being listened to by their prosthetist and that the result of this was that they had their prosthetic needs met. However, there were a small number of exceptions where the men did not feel that their prosthetist was listening to them. For some this could be seen to lead to breakdown in the relationship between themselves and their prosthetist. For other men they felt that not being listened to had resulted in them being provided with a limb which they felt was not suitable or fit for purpose. One of the men spoke about a situation where there was dialogue between himself and his prosthetist about what he wanted and the prosthetist explaining the prescription they had provided, despite this exchange there was a disconnect between them and neither appeared satisfied with the outcome.

“If you know her you know what I'm talking about. Right, they put carbon in it, you'll see it in the light...right, I'm fed up telling her 'keep it low' cause once I get it home I can get my [power tool] out...Little bit of home adjustment and then I can get my heat gun out and curve it, but once you get to the carbon fibre inside you can't bend it any further and that's still too high. And she keeps moaning at me, if you take it any lower it'll not fit right. It doesn't matter, I want my leg to bend and I am quite active.”

(Ted, civilian amputee)

Jack and Douglas talked about their experiences of this in both the NHS and MOD settings. Both men felt that since coming back into the NHS the care they had received

made them feel that their needs and opinions were valued by the clinical team. They felt that time had been taken to understand what treatment they had had at Headley Court and how that could be taken forward to help them achieve their goals. Douglas in particular spoke about how the NHS had provided him with a pair of bespoke limbs for rowing after he had said that this was something that he felt he needed in order to reach his goals after being discharged from the military. He had been unable to be provided with these by the military prior to discharge despite having approached his prosthetist at Headley Court about getting them.

It seemed that having their prosthetist listen to what they wanted along with the patient being able to see that the prosthetist had taken what they had said into account and incorporated it into their prescription helped the patients feel that they had been involved in the decision process.

It appeared that some of the participants had adopted a 'consumerist' approach to the interaction with their prosthetists. This was seen in cases where the men talked about asking their prosthetist for something quite specific prosthetically. This ranged from men asking for items such as swimming limbs, a pair of limbs for rowing or even a specific high end component such as the 'Flex Foot Cheetah'. Some men reported that they received these items in response to their requests; others however talked about there being a period of negotiation with their prosthetist in which certain goals had to be reached before they could be given a specific item or as was the case with Ted he was told that he was not eligible to get the component he had asked for based on its cost. When talking about Headley Court there was a feeling from some that 'the louder you shouted the more you got'. As well as this in a group rehabilitation setting such as Headley Court could influence your knowledge of what was available prosthetically and could have an impact on what they asked their own prosthetist for.

"I was speaking to a lad that was actually testing the Echelon VT, you know, I'd never even heard of it or anything, he was telling me about it and it was just the best of the Echelon and the Elite VT put in together and that's the one that I use all the time now. . . . Yeah, cause I asked them about the Echelon VT and says, like, 'I want that, that's exactly what I would like' you know, cause you've got the left and right and back and forwards and shock absorbing, 'see if we can get you one'."

(Chris, amputee veteran)

In contrast there were some participants who talked about appreciating being listened to by their prosthetist but that they felt that the prosthetist knew better than they did as a patient.

“Obviously, they know better than me when it comes to talking about something, but she listens to me and says, look, this is what I need and she’s great.”

(David, civilian amputee)

Sam showed a mix of both ‘consumerist’ and ‘passive’ approaches to his prosthetic care. On one hand he talked about trusting his prosthetist to do what was best for him but contrary to this he spoke about how on occasions he would take information on prosthetic components he had researched himself to his prosthetist to discuss.

Earlier in this chapter it was seen that these men interacted differently with their prosthetist over time. One patient further highlighted that he felt that there had been a change in his involvement in the process as he move from being a primary to an established amputee.

“At the start, probably not. I don’t think anyone is, really. I don’t think...because you’ve never been in that situation before, you’ve never been in that...you’ve never...I had no clue whatsoever what a prosthetist is...Yeah, like whereas before you just want to walk, and say for example now I can go into the prosthetists and say, right, there needs to be a mill higher or that’s not right, that’s not right, so you kind of pinpoint, whereas at the start, just give me legs, let’s see if I can 20 steps...You can’t be on a prosthetic leg for a week and expect it...yeah, I know, I definitely, I want this one.”

(Rory, amputee veteran)

Within the military there were similar reports of prosthetists going through the process of asking patients what they wanted to achieve as an amputee. In general these men reported that they felt that they had been involved in this process through discussion with prosthetists around what they wanted to be able to do and being given explanations around the process of starting with a more basic prescription and moving up from there. It was indicated that the prosthetists at Headley Court sought more quickly to provide a

prosthesis that would be suitable for a wider range of activities than in the NHS. There was some conflict in their views about what they might be given, where one thought that the requests they made had to be within reason, others experience was that what you asked for you got. For one of the men there was a feeling that he had not been involved in the prescription process but rather that his prescription had already been decided on because he was a bilateral trans-femoral amputee.

Key points

1. The majority of patients were satisfied with their involvement and saw this involvement as being asked what they wanted to achieve and their responses being listened to- they felt that they had been listened to when they were provided with something that enabled them to do what they asked to be able to achieve.
2. Not feeling listened to could lead to a breakdown in the prosthetist/patient relationship.
3. In some cases discussion is not enough and there still seems to be a disconnect between the prosthetist and patient leaving feelings of dissatisfaction.
4. Patients seem to have different approaches to their prosthetic care. But commonly in this group patients approach was quite consumerist where patients seem to see their prosthetist as needing to react to their requests
5. There seemed to be more variability on feelings of involvement in the MOD than the NHS
6. There was a feeling that they were more equipped to be more involved in the process over time.

7.3.2.2 Accessibility to care

Commonly these men discussed the process of care that they had received at the beginning of their rehabilitation. The majority spoke about meeting the whole of the MDT together as the starting point for their rehabilitation. For those who had lost their limb at injury they met them as a new amputee but for those such as Gavin who had an elective amputation he met them prior to his amputation. Reports from the civilian group showed that there was a mix between those who had undergone their initial prosthetic rehabilitation as outpatients or not. This distinction meant that a proportion of these men received the physiotherapy associated with their prosthetic rehabilitation outwith their disablement services centre (DSC) at a location closer to their homes. For the remainder of this group initial physiotherapy was provided at the DSC.

Each of those in the military group reported getting their prosthetic rehabilitation as inpatients at Headley Court where they attended on a full time basis for blocks of time. These blocks of time varied in length but were always interspersed with rest periods

during which they convalesced at home. During the periods they were at Headley Court they received a variety of rehabilitation including prosthetic, physiotherapy, occupational therapy and medical input as well as additional physical training. These men talked about having good access to input from each profession throughout their time in-house, each met with their consultant on a weekly basis who kept an eye on their progress and instructed the rest of the clinical team on their care package. Each of these men spoke highly about the facilities and the care they received while they were there. What a number of men in this group highlighted as a particular benefit was the group rehabilitation environment with men who had experienced similar injuries in comparable circumstances. As discussed earlier seeing others further through the process helped these men to see what they could achieve in the future. One man in particular saw his achievements as an amputee as attributable in part to this group rehabilitation combined with the ethos instilled by the military.

“But the regimental system in the British army is very, very fierce, very competitive. There’s lots of regimental spirit and pride, so you’re always...you’ve always got that competitive edge at Headley Court, and then there’s other guys who are not in the Marines or the Paras, but they want to fight to get one up over on it, you know, so we drag each other on...We’ve been in that place and that hub together and it being so intense, you know, it’s full-time, ’cause you’re there nine to five every day...we all travelled together. Yeah, yeah, a lot of group therapy, yeah.”

(Douglas, amputee veteran)

For Colin, even though he received his prosthetic care in the NHS he attended Headley Court for blocks of physiotherapy and physical training. He talked about enjoying being at Headley Court and meeting other amputees, in his own battalion he felt isolated as he was the only amputee so he felt that they were unsure how to treat him but felt that he got great care at Headley Court.

“Aye, well they says...it was like every couple of months, but I wanted to be down there all the time so I was getting the right fitness and the right amount nutrition and the right amount of help because, as I says, my battalion, I was the first one, like first amputee they had encountered so I don’t think they knew how to handle me.”

(Colin, amputee veteran)

Civilian patients spoke both positively and negatively about their access to prosthetic services. One aspect they spoke about was the speed at which they could get an appointment. The majority felt that this happened in an acceptable time frame and some reported that they could be seen on the same day if necessary. Only Ted indicated that he felt he had to wait too long for an appointment, having to wait up to seven weeks on occasion. Access to physiotherapy services was discussed as an issue by a number of the men, for some it was seen as difficult to access additional physiotherapy input after their initial limb fitting and gait training. Others reported having access to continued physiotherapy but felt that the benefits of having that input were outweighed by the length of the journey to get it. Finally, one man felt that the physiotherapy he was offered was not challenging enough and as a result had stopped attending for physiotherapy appointments, it was his feeling that his physiotherapist did not have experience of working with fit trauma amputees.

For military patients there were problems raised around there being only one site for prosthetic care delivery for service amputees. There were issues about travelling to and from Headley Court for each of the blocks of in-house care and the difficulty in being able to get home for weekends when they were able to leave if they lived far away. Further than this one participant talked about how he had to travel to Headley Court for all aspects of prosthetic care right up to discharge which had major travel implications and was perceived as being impractical both for the MOD in terms of cost and unsatisfactory for him. There was a general feeling among this group that there had been a decline in the quality of care at Headley Court over time. For some it was a lack of continuity of prosthetist that they commented on and for others it was the access to their prosthetist and general increase in the number of amputees that were attending during the time they were there impacting on the care that they felt they received.

Key points

1. Military patients saw great benefit in being able to rehabilitate in a group setting with men who were in a similar position to themselves.
2. MDT collaboration is more evident to patients in the military rehabilitation setting and they appreciated this group approach to their rehabilitation.

7.3.2.3 *Why I have what I have: Patients' understanding of prescription*

7.3.2.3.1 Patient understanding

A number of participants were able to identify specific links between the design of their prostheses and the rationale for those decisions. For some they were able to link problems that they had previously had with suspension to a new prosthesis design. These men identified that different suspension methods were tried in response to reports they made to their prosthetist about issues they were having. As well as this some of the men had an understanding of the reasons which were specific to them that explained why certain methods of suspension did not work for them. Other men attributed their prescription to the level of activity that they were involved in, particularly in the case of Sam and Colin. David identified the change in his prosthetic foot prescription to a carbon fibre model as a result of having collapsed the heel of a number of the feet he had previously been prescribed. Colin talked about feeling that there were a number of separate reasons for having been prescribed the limb he had.

"I was playing football, I was doing the weights, I was running. When I was in the Army I was doing everything basically. I think because I was in the Army and I was doing so much activities I got this leg."

(Colin, amputee veteran)

Rory spoke passionately about the military and felt that he had been prescribed what he had because he was part of a unique patient group who have a unique mind-set and drive to achieve their goals and that they should have access to the best components that will help them achieve it. He did not feel that this should be handed to them on a plate but that it was something that they should be able to push for.

"You get the odd...certain guys don't push for it, you always have that one per cent of squaddies that kind of...the world owes you something and I shouldn't have to do what I don't want to do, type thing, but that's up to them."

(Rory, amputee veteran)

Some of these observations could be put down to the individuals' appraisal of their situation. However, there are some points and associations which they make which would indicate that they have had them explained to them, either by their own prosthetist or another member of the clinical team.

7.3.2.3.2 Other health issues

A number of the men identified other health issues which they saw as impacting some aspect of their prosthetic rehabilitation. Four of the participants, a mix of military and civilian men, had experienced a variety of issues associated with their original injury or accident which affected them prosthetically. For one man it was psychological problems resulting from the situation in which he was injured the prevented him from sleeping which he reported making progress at different stages in his prosthetic rehabilitation. For the remaining three men it was other injuries sustained at the time of the original accident which had been and continued to impact on their prosthetic progress.

"I don't think it's anything to do with the leg that I'm not walking, my prosthetic that I'm not walking well. [Wife talking] Yes it's just my knee, and obviously the pain I was getting in my shin which... like I say, if I get up and walk now it'll be quite difficult but it will ease off and I'll be able to walk a bit better, you know."

(Frank, civilian amputee)

"You really need it for this leg, this leg's the problem. If this leg was normal I'd be back at work, I'd be doing some other kind of job of some sort, know what I mean, I wouldn't be sitting here, I'd be doing something. It's this leg that legs us down. That's that really."

(John, civilian amputee)

"With me, for instance, because I had so many different injuries I was constantly having setbacks and probably my personality as well trying to, you know, kind of, run before I could walk, it probably never helped. And there were constant setbacks and, you know, more surgery, constantly needing things for the first proper year of being an amputee."

(Jack, amputee veteran)

Frank and John both stated clearly that it was these other injuries which held them back and not the amputation or the prosthetics themselves. With Jack the nerve damage he sustained to his non amputated foot continues to affect his gait.

A further three participants talked about problems with their residual limbs which had resulted from wearing a prosthetic limb and made it difficult to wear their prostheses at times. For one of these men these issues had raised discussions about revising the level of amputation which they were keen to avoid as they perceived that this could decrease his level of mobility. David, who had been a prosthetic limb wearer for the longest, spoke about becoming less mobile with his prosthetic limb than he had been previously. He attributed this to 'shrinking of his stump' over time leaving his bones more prominent and prone to getting sores. In addition he had experienced increasing nerve pain in his stump which prevented him from wearing his prosthetic limb for only 15-20 minutes at a time. As a previously very active limb wearer his perception was that this had caught up with him resulting in osteoarthritis in the knee on his amputated side which also impacted on his limb wearing and ambulation.

Key points

1. Participants understood that it was not their amputation in isolation which affected their prosthetic rehabilitation understood some of the other health issues which could have an impact.
2. Participants understood that there were other factors outwith their prosthetists control that could impact on what they were able to achieve post amputation.

7.3.2.3.3 What it costs

Six of the men who I interviewed discussed financial cost as part of their understanding about what they had been prescribed prosthetically. This was discussed in both the MOD and NHS settings. In addition there was also discussion around cost in relation to private prosthetics companies involved in insurance claims.

Influence of private care

Three of the civilian participants discussed the cost of prosthetics in conjunction with their experiences of private prosthetic care. Two of these men had attended private prosthetic companies for a prosthetic assessment associated with insurance claims from their accidents. Neither of these men subsequently received any private prosthetic treatment but used the experience of private assessment as a backdrop for discussion around cost issues of their NHS prosthetic treatment. It appeared that this private assessment had left them feeling dissatisfied with the quality and cost of the prosthetic limbs they were provided with by the NHS. One participant explicitly felt that the NHS would provide the cheapest prosthesis they could while both of them felt that what they were prescribed by the NHS was inferior to what they would have been provided with

privately. This could have been an opinion which was instilled by the private company themselves as Ted reported that when they had described the limb he had been prescribed by the NHS as a 'joke'. Conversely Sam who had received prosthetic care from a private company as well as the NHS was very happy with the prostheses he had been provided with by the NHS. He felt that the limb he had was the best and the most expensive that they could have prescribed him and on balance he felt that the care he had received from the NHS was better. The last thing that he reflected on was that having met other young active amputees in the UK he had realised that he was lucky to have been provided with what he had by the NHS.

"like when I was on the adventure rehabilitation course there was another couple, two or three people with the same, like a below the knee amputation, and one of the girls was absolutely flabbergasted that I got that leg on NHS . . . yeah, and that she was being given the absolute bog standard basic limbs and this was like a 25 year old girl, and that was it, she was absolutely shocked that you could get something as good as this on the NHS"

(Sam, civilian amputee)

One of these men reported having been refused a specific prosthetic component he had requested after seeing it advertised, the reason that he was given was its cost. He felt that their refusal to provide that component was holding him back. In general he was disparaging about the money and costing among NHS prosthetic prescription.

"Well, instead of the NHS hitting you with a lump of junk, right, [expletive] knows how many times over the years that you're an amputee, why not spend the money on decent limbs that's going to last a lot longer and they'll probably save money, that's the way I look at it, they'll save money in the long run if they spend money on decent limbs and they're not going to have folk going back and forward/back and forward, this is wrong/that's wrong, it's not doing this and it's not doing that, you know, cause every time I go up there it's the same faces all the time, there's something wrong with their leg."

(Ted, civilian amputee)

For each of these three men their interaction with the process of claiming insurance and subsequent appraisal by private prosthetic companies seemed to cloud the way they

viewed the NHS prosthetic components they had received. For Ted and Frank this seemed to have a negative impact but for Sam it appeared to have a positive effect.

In the military

Two of the military participants had conflicting opinions regarding the cost of limbs provided by the military. One felt that there was no restriction on the money that could be spent on prosthetic components for war injured personnel and that in his opinion this should be the case. Conversely the other man talked about having gone through the process of making a case for being prescribed a pair of Genium knees prior to being discharged and understanding that these components were not available to everybody who wanted them.

“And you don’t get the fancy legs unless you shout really loud.”

(Douglas, amputee veteran)

In addition there was a sense from one of the military participants that there were service amputees who were used by the MOD as examples of what could be achieved in the field of prosthetics and that they could be seen to enable that to happen, he felt that these men were not restricted in the cost of the prostheses that they were provided with. Finally he felt that there was an element of some of the military guys just wanting what was new, shiny and the most expensive.

Only one military participant spoke about the availability of specialist prosthetic components for veterans through the NHS. In his experience his consultant had acted as his advocate to push for finance through the specialist prosthetic veterans fund in England for him to be provided with one of the most sophisticated prosthetic knee joints in the world.

Key points

1. Some patients associated the cost of their limb to their satisfaction with it.
2. Patients satisfaction could be affected if they felt that cost had restricted what they had been given, conversely, if they felt that they had been given the most expensive thing this could increase their satisfaction.

7.3.3 Transition from the MOD to the NHS

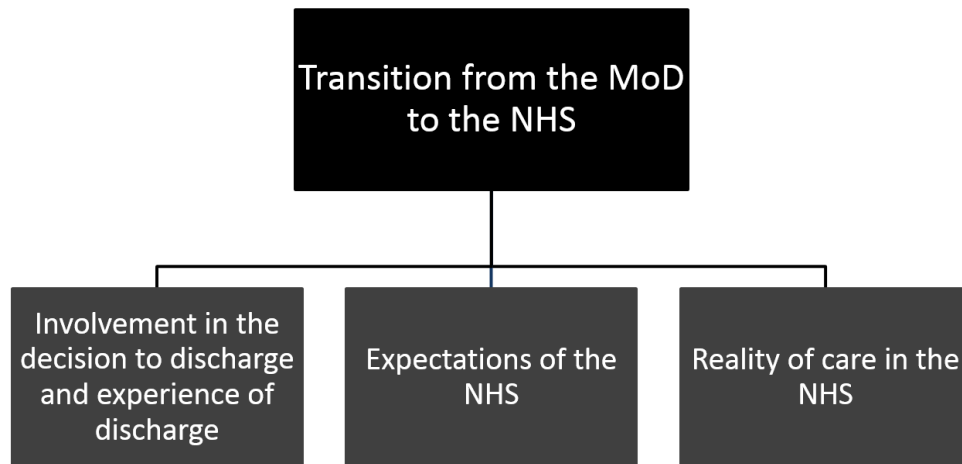


Figure 23: Transition of care theme structure

This final category focussed on the other primary area which was discussed during interviews with amputee veteran patients around the process of transition of prosthetic care from the MOD to the NHS. During the collection of this data I was able to gain insight into the prosthetic care received by patients in the MOD as well as information about the process of decision making to discharge from the services. The four themes within this section therefore reflected the breadth of this section of data; ‘The personal meaning of discharge’, ‘Involvement in the decision to discharge’, ‘Expectation of the NHS’ and ‘Reality of care in the NHS’.

7.3.3.1 Involvement in the decision to discharge and experience of discharge

For each of the five men in this group the decision to discharge was taken as either a direct or indirect result of having suffered an injury while in service resulting in an amputation(s). Douglas and Rory talked about this as a decision which was taken for them by the military to be medically discharged. These men’s experiences of discharge were similar, both talked about realising soon after their accidents that their injuries would result in them being discharged from service. Douglas distinctly remembered one of his superiors telling him “we don’t keep wounded guys anymore”. Despite reporting that they were aware that they would ultimately be discharged from the military for both of them the official decision was not taken until several years after their accidents had occurred.

The other three men Jack, Chris and Colin ultimately took the decision to be discharged themselves. Each of their accounts indicate that they were either sure they could have remained in service had that been their decision or that, as in Jack and Chris’ cases,

that they felt no pressure to leave and would have been able to stay had that been there choice. For Chris the process of decision making was pushed by him following a long period of rehabilitation during which he felt he did not know what was going to happen to him next.

"I got so sick and fed up of... in the end, of being injured, being in the army, in this complete sort of limbo state, you know, it was three years of just 'am I getting out the army/are they going to keep me in/what's happening with this/what's happened with that?' and I just wanted out in the end."

(Chris, amputee veteran)

At that stage he spoke about being asked if he wanted to stay or go but he knew that he wanted to leave. Similarly Jack talked about it being his decision to leave but had felt that if he had wanted to stay then that would have been a possibility.

"I mean it's never something I personally wanted but probably if I had pushed it there wouldn't have been any reason why they could have made me leave...I think it's a case of if you can prove your fitness to them, when you prove you can still do the job then. I can't see them forcing me to leave, but like I say it was never really an option for me, I didn't really want to stay."

(Jack, amputee veteran)

Colin, who was injured earlier in the conflict in Afghanistan than the other four men, reported that he had received a lot of negativity upon his decision to be discharged. Douglas, Jack, Chris and Rory never returned to any sort of work in the Services after their injuries. However, at the time he decided to be discharged Colin was working in a supply role at his barracks. He was offered another office based role and it was at this point that he decided he wanted to leave despite efforts being made to get him to stay.

"I was working in the stores with the QMs and I got told I'd be working like doing a clerk's job and I was like that, give me my papers, I want my discharge papers...they tried everything to keep me in but I just...I didn't want to sit in an office and deal with people's pay cheques and all that. I wanted to be back out there."

(Colin, amputee veteran)

7.3.3.1.1 The personal meaning of discharge

The men's varying experiences in their involvement to discharge was also reflected in the differing meaning that that decision had for each of them. For Douglas the knowledge that he would be medically discharged was a great distress in the beginning as he spoke about begging to be allowed to stay in the beginning. He spoke about it taking time and being a hard journey as well as requiring input from other personnel for him to reach the position where he realised that being discharged was the best thing for him. It took him the time from when he first realised that he would be discharged until he was actually discharged three years later for him to feel ready to go.

The thread that runs through each of these veteran accounts was the realisation from each of them, at some stage before they were officially discharged, that even if they remained in service they would not have been able to do the job that they had joined up to do. Their accounts showed a strong link between not just being the services because it was a job but that the actual frontline fighting was what they wanted to do and if they no longer could then they would be better off being discharged.

"Aye, they tried everything to keep me in but I just...I didn't want to sit in an office and deal with people's pay cheques and all that. I wanted to be back out there. People say I'm mad because I wanted to be back out there fighting."

(Colin, amputee veteran)

"I just wanted to get out in the end cause I knew that I was never going to be able to return to the frontline or, you know, go back out to places like Afghan and that, so for me it was just pointless staying in the army."

(Chris, amputee veteran)

"I joined the parachute regiment to kick doors in and kill the Taliban. I didn't join it to count blankets and stuff like that, so...yeah."

(Douglas, amputee veteran)

“I weren’t happy, but it was just a realistic observation, really, that I couldn’t do what I was doing ever again, so what’s the point of me staying in.”

(Rory, amputee veteran)

There was also the aspect that without being able to do the job they had been trained to do then their promotion trajectory within the Services was also compromised. While leaving the Services for some was not their first choice, it was a pragmatic one which they felt would benefit them more in the future. Each of the men I interviewed in this group had undergone amputation in their twenties. Therefore for each of them being an amputee and what that meant involved them looking far into the future and considering what they wanted from their lives after discharge from the Services.

7.3.3.1.2 Time to discharge

As mentioned above often years elapsed between injury and the formal decision to discharge being made. A possible reason for this was described by two of these men. Douglas talked about being kept in the Services until the point when they felt that they had done everything they could medically and rehabilitation wise, this included him staying on a further six months from his original discharge date so that they could provide him with updated prosthetic knee components which were only just starting to be prescribed at Headley Court. Chris talked about feeling that he could have stayed longer and been provided with more prosthetically if he had wanted but had pushed the decision to be discharged before that point.

7.3.3.1.3 Transition itself

The process of transition itself varied between the men. It seemed that the variations in their experiences of the process of discharge were linked to when they were discharged. Even during the time I was collecting this data there were changes made to the process of transition of prosthetic care from the MOD to the NHS. This section only discusses the experiences of four of the military participants as Colin never received prosthetic care at Headley Court.

The other four men were injured and discharged for service during the period when Headley Court was the sole prosthetic centre for military personnel. When they were discharged a process of handing the responsibility of their prosthetic care from Headley Court to the NHS was needed. The accounts of Chris (injured 2009, discharged 2012), Jack (injured 2009, discharged 2012), Rory (injured 2009, discharged 2012) and Douglas (injured 2011, discharged 2014) show how this process changed over time. Chris, Jack and Rory were injured and subsequently discharged around the same time,

each of them talk about the transition of their care as a process which could be improved. Chris was not informed by the military how the transition of care should happen. Not long after he was discharged there was an issue with one of his prosthetic limbs so he attended his local limb fitting centre where they had no knowledge of him and he was told that he would have to get a referral from his GP before they could treat him. After this there were then issues with his prosthetic notes being transferred from the MOD to the NHS. Similarly for Jack he talked about approaching his local DSC prior to being discharged thinking that he was doing the right thing in preparation for his transition from the Services. As with Chris, Jack felt that there was a lack of communication to him about what would happen for him prosthetically after discharge. He talked about feeling like he had 'come up against a brick wall' when he spoke to them. There was a lack of communication between the DSC and Headley Court about how the cost of the level of prosthetics Jack had been prescribed at Headley Court would be covered once he was discharged. Jack also spoke about the difficulty in having his prosthetics notes transferred to the NHS after discharge. His opinion was that the process of handover from the MOD to the NHS should be started up to six months ahead of actual discharge. This would make the process less stressful and much smoother.

Rory also spoke about having introduced himself to his local limb fitting centre a number of months before he was discharged. His experience with Headley Court was that they did not release any of his paperwork until only a week before discharge. It was therefore hard to achieve anything meaningful by way of transition of care. He felt that this made it quite a difficult process.

Douglas was however discharged around two years later than the other three men and his experience of the transition of his prosthetic care was very different. Prior to discharge he attended a 'hard facts meeting' where he met one of the prosthetists from the centre he would be attending after discharge. This meant that the centre were made aware of him being transitioned to them in advance of it happening and they were able to meet and start a dialogue and answer any questions Douglas had. Douglas spoke very positively about the transition process.

These changes in experiences reflect the changes that were happening in the process of transition at the military level and their increased interaction with the services that their personnel would be in contact with after discharge and allowing them the opportunity through the hard facts meeting to meet with them before they reached the point of discharge.

7.3.3.2 Expectations of the NHS

As discussed above only four of the men interviewed had experienced receiving prosthetic care at Headley Court prior to being discharged from Service and subsequently receiving their continued prosthetic care in the NHS. This theme explored if they had any pre conceived ideas about what prosthetic care would be like in the NHS before they were discharged and where those ideas had come from. Only one of the veteran patients indicated they had no pre formed expectation of the NHS prior to discharge. The other three talked about having been told during their time at Headley Court that once they were in the NHS that they would no longer be getting the same level of care. One felt that there was widespread attitude from personnel at Headley Court that those being discharged should try and get as much as they could from the military because they would not be able to get anything once they were back in the NHS. His perception was that the prosthetists there saw the NHS as the 'big bad wolf'. This was mirrored by one other who talked about being told horror stories about the NHS which was unhelpful for those going through that process of transition. Conversely the remaining participant in this group talked about having taken these stories as a warning and was glad that he had had that.

The other expectation which was spoken about was related to what they understood were their rights as veterans within the NHS around priority care for them in the NHS and that there was funding available so that discharged amputee veterans would still have access to prosthetic limbs equal to those provided by the military.

7.3.3.3 Reality of care in the NHS

For some their first experiences of the NHS were more in line with their expectations of poor care. These men began attending their local DSC after discharge but asked to be transferred to one of the specialist veteran centres after a period of what they felt was sub-optimal prosthetic care locally. One reported that his poor experience resulted from his interaction with the prosthetist he got directly after discharge. His perception was that this prosthetist was worried about how their service would fund the care he needed and that they were not interested in trying to do the best for him. Another participant had a difficult experience initially but not as extreme, his local centre was not C-leg certified when he was first discharged and that he had to push for them to have that training. In both of these cases after transfer to the specialist centre they reported the high standard of prosthetic care they received there and the enthusiasm and drive of the clinicians there to get the best thing for them in order for them to achieve their goals.

“Yeah, I mean even this, you know, I've got this world record attempt coming up next month and I'm going into prosthetics next week and they are getting me the guy who helped design Jamie Peacock, the 100 metre Olympic sprinter who designed his leg - they've got him coming in to maybe look at making me a different leg, you know. They don't have to do that, they just did and they gave me the basic, so you know, what I need really and they are asking me what they can do to make things better. So little things like that, you know, that doesn't cost anything, you know, that's just a case of booking an appointment for me with this certain guy and they are doing [everything they can for me so that definitely goes a long way.”

(Jack, amputee veteran)

In contrast, Douglas stated that his experience of prosthetic care in the NHS was the exact opposite of what his expectations had been prior to discharge, even saying that he was more satisfied with the care he had received from the NHS. Similar to the previous accounts he attributed his satisfaction to how he felt that the NHS clinicians' wanted to help him achieve his goals and had worked with him to make that happen. He spoke about their being aspects of the care that he had received from the NHS that Headley Court could learn from as well as the other way round.

Key points

1. The military appear to discharge their injured personnel when they feel they have achieved as much as they can even if they know that they will ultimately be discharged from early on in the process.
2. There appears to be a feeling that there is no place for injured personnel in the military anymore and that discharge is a more viable option for a fulfilling future than remaining in the military injured.
3. This group had joined the military to serve a particular function and if they were no longer able to do that then they felt it was better to leave.
4. The process of transition of prosthetic care from the MOD to the NHS appears to be improving as a structured process is put in place to handle this transition.
5. Personnel at Headley Court including prosthetists working there are creating a picture of the NHS as an inferior prosthetic service provider.
6. More commonly veterans identified that this was an unhelpful and unrepresentative view of NHS prosthetic services having received prosthetic care in the NHS since military discharge.

7.4 Conclusions

The findings from this chapter indicate that trauma patients can only be involved in the decision to amputate under some circumstances. In the circumstances where they are able to participate in the decision (to have an elective amputation) participants valued the opportunity to see others who had also gone through the process and who they could see their mobility improving as a result of amputation. The ability to be involved in the amputation decision combined with the mode of amputation seemed to influence the way that they adjusted to being an amputee.

Following on from amputation, these men articulated what effect amputation had had on their functioning and spoke frequently about the negative effects that amputation had had on their ability to return to their previous job. This group of men had a wide variety of goals and aspirations; some felt that these had to be adjusted over time in relation to their abilities with their prostheses. Each man was able to articulate the factors relating to their life as an amputee that had influences their ability or inability to achieve their goals and aspirations over time, they could identify that not all of these were related to the care they had received from their prosthetist. They identified that they understood that their ability to achieve their goals and aspirations was also related to other factors such as further injuries and comorbidity.

This group of men articulated the importance of developing a good working relationship with their prosthetist. The building of a relationship could be seen to be related to shared interests between the prosthetist and the patient as well as continuity of care in the initial rehabilitation process and over the following year, some of the men in this group linked the quality of their prosthetic care to the continuity of care they received. Data indicated that some of the members of this group's satisfaction with their prosthesis was connected to its cost. Some were dissatisfied with their prosthesis when they felt that cost has restricted what they had been given, conversely other participants were satisfied with what they had been prescribed because they related it to being the most expensive thing that they could have been prescribed.

There were aspects of the organisation of the prosthetic care setting in the MOD and NHS which were noted to be better in one or other setting. Continuity of care in the MOD setting was seen to be less consistent than in the NHS setting, those transitioning to the NHS saw the barriers of a lack of continuity of care in the MOD rehabilitation setting and appreciated the continuity of care they received in the NHS. MOD participants also identified the volume of patients attending Headley Court as a negative aspect of their

care there. Continuity of care within the NHS was seen as beneficial from both the perspective of veteran and civilian participants. Only in one case was continuity of care seen as detrimental to their care. Conversely the group rehabilitation setting was identified as a strong benefit of rehabilitation with the MOD setting. These men felt that once back in the NHS the process of rehabilitation was a much more personal journey. They felt that group rehabilitation had helped them to feel that they could achieve more than they felt they could have on their own, it felt supportive rehabilitating with others in a similar situation.

The participants in this study indicated that in the majority of cases they were satisfied with the level of involvement that they had had in their prosthetic care. They identified this involvement as being linked to discussion they had had with their prosthetist and feeling that their contributions had been listened to. Some identified feeling that they had been listened to if they were provided with a limb that enabled them to achieve what they wanted to. Their feelings of being able to take part in that discussion and therefore be more involved was felt to be something that they were unable to do as a primary amputee but developed over time. In the cases where participants felt that they were not able to do what they had articulated to their prosthetist they wanted to be able to do this was viewed as not having been listened too, this could lead to frustration and dissatisfaction between the patient and their prosthetist or an irreparable breakdown in the working relationship if this happened over a protracted time period. There appeared to be a discrepancy between participants' feelings of involvement between the MOD and the NHS setting. Accounts from this group of participants indicated that the interaction they had with their prosthetist was quite consumerist in nature, a number of them saw their prosthetist as someone who needed to react to their care requests.

Rehabilitation within the MOD was identified as being of a high standard and that this group of men had been able to receive that level of rehabilitation until they reached a good level of function prior to medical discharge. This group were thankful for having had the opportunity to have their rehabilitation in a setting of the level of Headley court where they were able to see the benefits of the MDT rehabilitation environment. Among veteran participants there was the feeling that the MOD instilled low expectations of the prosthetic care that they would receive once they transition to NHS care. Most of the members of this group had found that these low expectations were not founded and were surprised and satisfied with the level of prosthetic care they had received as well as the access the NHS was able to give them to state of the art prosthetic components.

Accounts across this group seemed to indicate that the process of transfer from MOD prosthetic care to NHS care was improving over time.

8 Chapter 8 - Discussion

8.1 Introduction

The main driver for this thesis was a perceived lack of research based knowledge in professional decision making within prosthetic care and the lack of research into patient perspectives of prosthetic care. It was conducted within the context of wide spread speculation about changes in the landscape of prosthetic care delivery in the UK's NHS. At the time it was suggested that there would be a sharp increase in the number of service amputees being medically discharged from the Armed Forces from recent conflicts in the Middle East, with the result that their future prosthetic care would become the responsibility of the NHS. This transfer of prosthetic provision for these patients from the Ministry of Defence to the NHS had raised fears from different quarters; NHS, Service charities and the Armed Forces community. Charitable organisations involved in the wellbeing of servicemen and veterans were concerned about the level of care that their injured amputee veterans would be able to receive in the NHS. There was concern from within the NHS that they would not be able to meet the needs of this group of patients financially or in terms of the expertise required to maintain the state of the art (SOTA) prosthetic components that they had been provided with while under MOD care. The NHS also had concerns around anticipated inequity of prosthetic provision between veteran and civilian amputees within the NHS. Unfunded commitments to improve prosthetic care for veterans made by the health minister in a written ministerial statement (O'Brien 2010) further fuelled these concerns. This was also combined with the knowledge that the Armed Forces had intimated that there would be an increased number of amputees leaving the Armed Forces from recent conflicts up to 2020 (Murrison 2011).

8.2 Summary of main findings

The scoping study identified that there was interest from both the NHS and the MOD in research which aimed to understand prosthetic decision making and the care of amputees across both settings in order to share ideas and best practice. However, despite initial interest, MOD approval was ultimately not granted for interviews with prosthetists working within the MOD or current military amputees. As a result, the study was conducted solely in the NHS but included an increased number of veteran amputees now living in the community, as well as the addition of interviews with prosthetic service managers. This allowed for an exploration of both patient and professional experiences

of prosthetic care and decision making and to explore the contextual barriers and facilitators to providing prosthetic care for traumatic civilian and veteran amputees in NHS Scotland during this time of change.

The research was conducted as two studies, Study 1 (Chapter 6) focussed on professional perspectives and decision making addressing the research question:

- What factors (clinical and non-clinical) are used in the judgement and decision making of prosthetists during prosthetic prescription for civilian trauma amputees and service attributable amputees?

Findings indicated that prosthetists viewed themselves as autonomous in the decision making process and that they were confident in their own experience and on occasion drawing on the experience of their peers to assist in the process. The study highlighted the important contribution of the physiotherapist however, prosthetists rarely mentioned rehabilitation consultants as being part of the decision making process. Instead they talked about them working in a medical capacity in the MDT in relation to amputee patients. These views were corroborated by all physiotherapists with only one consultant feeling that they were more involved in the process of prescription than the prosthetists at that centre had indicated.

The main factors identified by prosthetists in their prescription decisions were weight, both that of the patient and of the available components, the presence of scar tissue and residual limb length as well as financial restraints. In addition, a patient's activity level pre-amputation and predicted future activity level were key in their decision process. These aspects were understood through the knowledge prosthetists gained from discussion with their patient around their goals and aspirations as a prosthetic limb wearer. These goals and aspirations were seen as a major influence on the prosthetic prescription in some cases defining the prescription, overriding the prosthetists desire to prescribe other components which would further increase the patients' functionality (see section 6.2.2.2). Patient feedback was important, without it prosthetists found the decision process more difficult, it was a key factor in evolving patients prescriptions over time and in understanding their goals and aspirations both as a new amputee and as they progressed.

Several other key findings arose from the analysis in Chapter 6. Firstly that prosthetists' decision making was a longitudinal process, revised numerous times over a period of years (see section 6.3.5.2). In some cases this could be seen as prosthetists prescribing something that may not be optimum but would 'do the job for now'. Secondly it was

found that there was variation among the ways that different patients interacted with their prosthetists, some were passive while others were seen as having a more consumerist approach. This consumerist approach was linked more commonly to their younger patient group. Thirdly findings related to the importance that prosthetists placed on the relationships that they were able to build between themselves and their patients and the role that cultivating a relationship over time could play on the prosthetic prescription process (see section 6.3.1.2). Lastly there was a key finding relating to the sources of knowledge that prosthetists reported using depending on the complexity of their patients' case. These included discussion with their peers and other members of the MDT, access to technical, promotional and limited research literature as well as being able to get borrow units to trial with their patients before making a definitive prescription choice. Prosthetists saw research literature as being the least accessed and helpful source of information in the prescription process.

Study 2 (Chapter 7) explored the patients' perspective for both civilian and military service trauma amputees addressing the following research questions:

- What are trauma patients' experiences of prosthetic care in the UK?
- What are the experiences of involvement in decision making in the NHS and the MOD of traumatic and service attributable amputees?
- What are the experiences of transition of prosthetic care for those amputees moving from the MOD to the NHS?

Findings indicated that participants' experiences of limb loss had a lasting impact on their ability to adjust and accept their change in physical status, this was true in both the civilian and veteran cohorts. Employment and the inability to continue with their chosen profession after injury was a common issue, some of the men reported having been able to adapt and find employment or other pursuits on which to focus, this was seen particularly within the veteran group. Others had been unable to return to any sort of work after their amputation, this was perceived as a continuing source of distress for these men. All of the amputee participants had an understanding of why they had been prescribed the prosthetic components they had been and that there were factors outwith their clinicians' control which affected what they could and couldn't achieve as prosthetic limb wearer.

Their feelings of satisfaction with their limb were associated with different factors. For some their satisfaction was linked to their understanding of the cost of their prosthetic limb. For others it related to a feeling that what they had been prescribed was linked to their prosthetist listening to their goals and aspirations and incorporating those aspects

into their prescription. The men spoke about feeling generally happy with their level of involvement and reported that their involvement increased over time. They felt that they were able to contribute during consultations more as they became an established patient than they could be as a primary patient. The men in this group held different attitudes regarding their interaction with prosthetic services, ranging from passive to consumerist interaction styles. The more consumerist approach was more commonly reported among the veteran group although it was also apparent in a few of the civilian group's accounts. The consumerist approach was also reported by members of the veteran group more commonly when they were talking about the process of prescription at Headley Court.

8.3 Comparison with existing literature

8.3.1 Prescribing prostheses

Some of the key factors that prosthetists in the current study reported as part of their prescription decisions were similar to those found in previous research carried out in the Netherlands. Van der Linde et al carried out a series of studies, a systematic review of the literature (Van der Linde et al 2004a), interviews with clinical experts (Van der Linde et al 2004b) and an observational study (Van der Linde et al 2003). The findings from each of these three studies were used as the basis for a consensus exercise to develop national clinical guidelines for the prescription of lower limb prostheses (Van der Linde et al 2005). Interviews with experts determined that there was a high level of agreement among the participants who reported that the level of activity of the amputee was the most important criterion in prosthetic foot prescription in transtibial amputees (Van der Linde et al 2004b). These findings were corroborated by their previous literature review which indicated different prosthetic feet prescriptions for patients of different activity levels (Van der Linde et al 2004a) and also identified the importance of current and expected level of activity in their prescription decisions. These factors of patient activity level were seen in the current study where prosthetists reported that predicted future activity was key to prosthetists decision making. Conversely, this study identified that pre-amputation activity level was also taken into consideration in this process, this was not identified in the research by (Van der Linde et al 2003; Van der Linde et al 2004a; Van der Linde et al 2004b; Van der Linde et al 2005). Sansam et al (2014) carried out a qualitative study with doctors, prosthetists and physiotherapists with expertise in amputee rehabilitation across four disablement services centres (DSCs) in England. The aim of this study was to gain a better understanding of how these professionals decided if a prosthesis should be prescribed and what components to prescribe in that situation.

They identified four main themes in their analysis; estimating outcome, difficulties predicting outcome, patient choice and barriers to prescribing. These four themes closely aligned to the findings from the current research. The focus of Sansam et al (2014) was the decision of whether to prescribe prostheses to primary amputees, whereas the current research has focussed more broadly on prosthetic prescription in both primary and secondary amputees. However, there are particular similarities in the reported findings of Sansam et al (2014) under the theme 'patient choice' where they discuss the sub themes managing expectations and patient goals and the importance of discussing both of these aspects with their patient during the prescription process. Each of these were raised by prosthetists in the current study as similarly important. A further key aspect they identified which was also identified in the current study was the consideration of the cost of different components when prescribing. This study was carried out at the same time that the current research was being undertaken.

Predicted future activity level was identified as a key factor in the decision making process in the current research. Prosthetists indicated that predicting patients' future activity level was easier in cases where the patient had undergone amputation as a result of trauma as these patients had not usually suffered a prolonged period of illness. Sansam et al (2014) also indicated that predicting future activity could be difficult. Van der Linde et al (2004b) found that future activity level was important in the prescription of prosthetic components, however, participants were not explicit about how they predicted this, and this was similar to the findings of this study. It was seen that prosthetists in this study did not report the routine use of any outcome measures in the prescription process, Van der Linde et al (2004b) also reported that none of the three groups of professionals interviewed commonly used outcome measure to assist in the prescription of prosthetic components. The factor which came through strongly from this analysis was the role that the relationship between the patient and prosthetist played. Additionally prosthetists reported the importance of patient feedback and its influence on the prescription, this was not reflected in the findings of Sansam et al (2014).

The model of decision making proposed at the end of chapter 6 has added to the body of knowledge both within wider decision making literature and more specifically decision making in prosthetic prescription. What this model shows is that prosthetists' decision making is dependent on their level of experience and the complexity of the case. The differences in decision making between novices and experts is supported by previous research (Dreyfus and Dreyfus 1986; Benner 2004) indicating that novice's decision making is more process driven, whereas those with more experience use a more intuitive

approach. Differences could also be seen in the way decisions were made based on the complexity of the case, the more complex the case the more process driven the decision was. The proposed model also shows that in some cases a decision is made quickly and without obtaining further information beyond the judgement phase but in more complex cases the converse is true. This concept of heuristic decision making, balanced in more complex cases by a more rational approach, is akin to the theory of dual process (Sloman 1996) or cognitive continuum theory (Hamm 1988) where intuitive judgement sits at one end of the continuum and analytical decision making at the other.

Decisions around prosthetic prescription were not affected by the constraints of time, which is cited as being a restriction on rational decision making processes within many healthcare settings. Decision making researchers have identified a relationship between the accuracy of a decision and the speed at which that decision was made, i.e. a decrease in the accuracy of a decision with an increased speed of the decision (Dane and Pratt 2007). In Chapter 5 (see section 5.3.2) it was discussed that while heuristics serve us well the majority of the time, they are associated with biases which will negatively influence those heuristic led decisions under uncertainty. Having identified that prosthetic decision making is not constrained by time this indicates that there is the opportunity for more rational decisions to be made by using a more systematic process in these decisions.

Other studies have focussed on factors affecting the use of evidence in prosthetic and orthotic practice. Andrysek et al (2011) found that prosthetists reported 'internet searches and asking colleagues' as the most common method for accessing information influencing their clinical practice (Andrysek et al 2011, p35). Similar to the findings in this research, they also found that peer reviewed journals were the least accessed source of information and that less than half of the respondents felt that they had the necessary skills to evaluate and implement findings from research to change their current clinical practice. Andrysek et al (2011) also highlighted constraints on time as influencing the uptake of evidence based information into prosthetic and orthotic practice. This has also been highlighted in an article that aimed to review the state of evidence based practice (EBP) within the prosthetics and orthotics industry (Ramstrand and Brodtkorb 2008). They reported that a lack of clinician time to search and appraise clinical research literature was a key criticism of the EBP model in the field of prosthetics and orthotics. They suggest that one of the reasons for adopting EBP into everyday prosthetic and orthotic practice is that it is one way of providing justification for the clinical service that is being provided to those who are responsible for funding those services.

This aspect of justification was reported by prosthetists in study two of this research and they reported this as being a difficult thing to do without sufficient clinical research literature. Prosthetics and orthotics can be seen to lag behind other allied health professions in their uptake of EBP; Andrysek et al (2011) proposed that this was due to the small size of the profession as well as a lack of research active members of the profession. The available research can be seen to increase year on year within orthotics whereas prosthetics research remains at quite a consistently low level (Ramstrand and Brodtkorb 2008).

Prosthetists identified their practice as evidence based and it was important to understand what they considered to be the components of their evidence based practice as they also reported that research evidence was not routinely incorporated into their day to day clinical practice, due to the quality and the lack of available research literature. Evidence based practice has been proposed as having four main influences; evidence from research, clinical experience, patient preference and available resources (Thompson and Dowding 2002). EBP worked originally on the premise that sources of information or evidence could be ranked, with systematic reviews and meta-analyses of RCT's considered to be the gold standard of evidence and expert opinion ranked the lowest (OCEBM Levels of Evidence Working Group 2011) and that research evidence was the most important component of EBP. However, more recently this has been challenged, with more emphasis placed on the contribution of the other aspects of EBP (Rycroft-Malone et al 2004). This debate mirrors the findings in this research by considering that clinical practice can be evidence based even where there is a lack of robust research evidence. The quality of the other three main aspects of evidence based practice must be made transparent in order to ensure rigour and quality in clinical practice. This includes the importance of the patient's input and involvement in their care which has also been mirrored in the findings from this current study. Attention to other aspects of EBP beyond research evidence will result in other sources of evidence becoming more robust and transparent, and taking into account the importance of the experience of the clinician and the input and preference of the patient in their treatment.

The findings in this thesis reported a strong 'consumerist' agenda among prosthetic patients; reflected in attempts by patients to be more involved or in control of their treatment and with reference at times to an awareness of limited choice and cost. This research identified that it was more commonly older patients who expressed a desire for their prosthetist to take a more paternalistic approach, this was similar to the findings of Deber et al (2007). They carried out secondary analysis of a series of survey and

interview based studies which measured patients preferred role in the clinical encounter including twelve different patient populations. They also found that older patients were more likely to take a passive role in their care, a finding also corroborated by other research (McKinstry 2000; Levinson et al 2005). Deber et al (2007) noted that when all twelve patient populations were analysed together for their preferences for autonomy 20.4% reported preferring to play a passive role, 78.1% preferred some degree of shared decision making and with only 1% preferring a totally autonomous or consumerist role. Similarly the current research identified a variety of patients' preferences for involvement in their prosthetic care but with both patients and prosthetists reporting more cases of consumerism than were reported in the findings of Deber et al (2007). Kraetschmer (2004) identified that increased familiarity with a clinical condition increased their desire to be involved in shared decision making. Similarly this research indicated that prosthetists and patients reported increased patient involvement over time as they became a more experienced limb wearer. Kraetschmer (2004) also reported the importance of the level of trust that the patient had in their clinician and its relationship to their desire to be involved in their healthcare decisions. This author identified that a lack of trust was linked to autonomous patient decisions; blind trust was related to a passive approach; and a high level of trust but without being excessive, was linked to those seeking a shared decision model. This echoes the findings of this project which indicate that the development of the relationship between the prosthetist and patient over time related to greater level of involvement of patients' in their care.

Prosthetists reported patients attending clinics asking for specific components, and this was not always well received by prosthetists. This negative effect of the increased availability of information regarding healthcare was highlighted by Mechanic (1996) who indicated that as well as patients being more informed they were also more likely to be sceptical of expert opinion.

Patients reported feeling that they had been involved in their care when they were provided with a prosthesis that enabled them to do those activities or tasks that they had indicated to their prosthetists that they wanted to do, i.e. when they felt that they had been listened to. This is similar to the finding from the thesis by Gravelle (2003) which indicated that patient satisfaction with their prosthesis could be increased with better communication between prosthetist and patient. In study two some patients indicated deep dissatisfaction towards their prosthetic care, attributing this in part to not feeling listened to by their prosthetist. Murray (2013) found that there needed to be better communication between the prosthetist and patient with more exchange of information

between the two in order to improve the prosthetic prescription process. Satisfaction in this group was varied but could also be seen to be linked to the cost of their prosthesis: some patients reported feeling dissatisfied if they considered that they could have been given something of higher cost, and others reported feeling satisfied because they felt that what they had been prescribed was 'expensive'.

8.4 Implication for clinicians, policy makers and future research

8.4.1 Transition from MOD to NHS care

The current research findings have implications for prosthetic care delivery both within the NHS and MOD settings. Findings indicate a need for better communication between MOD and NHS clinicians, both about the services that they are providing and about individual patient cases. Within the NHS it is common practice, when patients are transferred to another limb fitting centre that the receiving centre is given extensive notes about the prosthetic care and treatment that that patient has received up until the point of transfer. Interviews with service managers in this project indicated that there was difficulty in getting individual patient information from the MOD at transfer. In addition, despite trying to obtain information from the MOD a number of times, they report never being provided with information on the MOD's prosthetic prescription policy. This level of transparency would be helpful in the transition of patients from the MOD to the NHS. It was indicated that trauma patients being treated in the MOD could feel different and isolated from other patients they were being rehabilitated with e.g. the mode of amputation or the difference in ages between themselves (relatively younger) and other amputees.

Veteran amputees reported in some cases that there was a lack of continuity of care in their prosthetic care within the MOD, for some this was a result of a high turnover of prosthetists during their time at Headley Court, while for others it was the high volume of patients that their prosthetist was working with. In addition to issues with continuity of care MOD veterans reported that the staff at Headley Court had given them low expectations of the prosthetic care they would receive from the NHS after discharge from the Armed Forces. In some cases this had created feelings of fear and uncertainty around the transition of care from the MOD to the NHS. NHS prosthetists also reported feeling that veteran amputee patients had very high expectations of their prosthetic care. Some of these prosthetists feared that they could struggle to meet some of these expectations after discharge. Ultimately the majority of veteran patients reported that the NHS care they had received was better than they had anticipated from the

information provided to them at Headley Court. These findings are from a small group of men, however, they indicate that issues of continuity of care in the MOD and expectations of the NHS could be important. They may have an impact on the experience of amputees receiving prosthetic care and Headley Court and subsequently transitioning into the NHS after discharge.

8.4.2 Implications for NHS services

Prosthetists in this study saw themselves as autonomous decision makers who sought advice and information from other members of the MDT when required. This differs from the findings of a recent study carried out in England (Sansam et al 2014). When looking at prescribing practices across four centres in England, they identified that two centres used the traditional model of prosthetic prescribing by the rehabilitation consultant but in the remaining two centres both the rehabilitation consultants and prosthetists had a joint prescribing role (Sansam et al 2014). Professional guidelines also emphasise a multidisciplinary approach to prosthetic decision making (British Society of Rehabilitation Medicine 2003). The current research indicates that prosthetists working in the NHS in Scotland were more autonomous in their prescription process than was found in similar research (Sansam et al 2014) and outlined in existing amputation and prosthetic rehabilitation guidelines (British Society of Rehabilitation Medicine 2003). However, they were still found to work as part of a multidisciplinary team for the rehabilitation of amputee patients. The recommendation from these findings would be a revision of these guidelines to reflect the variation in practice between prosthetic services in England and Scotland and to reflect the increased autonomy of prosthetists working in Scotland.

The research shows that prosthetist decision making in this cohort are not constrained by time and that these prosthetists have access to a wide number of information sources to assist in their decision process. What it also shows is that prosthetists do not access these sources of information in each one of their prescription decisions, some decisions can be seen to be made intuitively whereas others are seen to be made through a process of consultation and information gathering. Which type of decision making is used could also be seen to be dependent on the experience level of the prosthetist and the complexity of the case. In an ideal situation more prescription decisions would be made using more of the processes of data gathering. In the real world this level of data gathering can't happen in every prosthetic prescription decision. However, the use of a decision tool could help prosthetists to go through a more systematic approach to making these decisions in order to help standardise their prescription process.

Patient participants who had received rehabilitation at Headley Court reported the benefits that they had felt as a result of being able to rehabilitate alongside others in a similar situation to themselves. Conversely a number of the NHS participants felt different from that. They were not like the average amputee in the NHS which could lead to them feeling different and isolated, as discussed in Chapter 2 (see section 2.1.1) trauma amputees make up only a small proportion of amputees in the UK. These findings suggest that trauma patients in the UK could benefit from having the opportunity to rehabilitate with other traumatic amputees where possible or to be able to meet with other traumatic amputees if desired.

Findings from Chapter 7 indicate the importance that prosthetists place on discussion with their peers in the decision making process. Almost exclusively this peer discussion was limited to other prosthetists working at their DSC. Van der Linde et al (2003) found in their observational study that prosthetists decisions appeared to be influenced by local experience of different prosthetic components as well as the implementation of new products. A further study by the same authors, using interviews with clinicians, found that most participants mentioned local experience of the prosthetist or consultant with a particular component as the criterion for the definitive component choice (Van der Linde et al 2004b). Similar to the findings of the current research they identified the important role that local experience and knowledge plays in prosthetic prescription. They concluded that it would not be easy to develop knowledge across prosthetic services in the Netherlands as a result of this reliance on local experience (Van der Linde et al 2004b). Each of these studies supports a broadening of the pool of experiences that prosthetists have to draw on beyond their peers in their individual DSC. The findings support the establishment of a central repository of prosthetists experiences of using different components with different types of patients. This approach would allow prosthetists to have access to a greater range of experiences to help inform their prescription decisions.

8.4.3 Implications for patient-professional interactions

Prosthetists and patients in this research reported the importance and value of forming a good relationship with each other. This relationship helped in terms of information available to the prosthetist which in turn helped them in their prescription decision. It allowed them to understand the patients' goals and aspirations and how best to meet these or to understand if some level of negotiation was required. For patients a good relationship helped them to feel that they were part of the process, particularly when they were able to see that their prosthetist had listened to them and taken their needs into

account. Prosthetists and amputees found that this was a relationship that evolved over time. In cases where there was a poor patient prosthetist relationship this could result in dissatisfaction with the prosthetic care and prosthesis provided. Prosthetists would benefit from being more aware of the advantages of a good relationship with their patient as well as the importance of patients feeling that they have been listened too. There should also be an awareness of the evolving way that prosthetic patients interact with prosthetic services. Reports from this research identify that trauma and younger patients are more likely to play a more consumerist role in their prosthetic care.

8.4.4 Enhancing research in prosthetic components

The new funding available through application for state of the art (SOTA) components for both veteran and civilian groups within Scotland's prosthetic services means that this service will have experience of components that have not previously been used. This new access to these components would support the recommendation that the service carry out testing and evaluations of these products. Randomised controlled trials would not be possible, as such, there has been some uncertainty about how rigorous evaluation might be conducted. However, other designs such as a series of n of 1 trials may offer a solution (Lillie et al 2011). The findings from these would help to inform to an extent the use and efficacy of these components. This would help add to the available research on components with the added benefit that this work would not be subject to the biases often associated with prosthetic component research carried out by the component manufacturers themselves. This supports the research and guideline recommendations within prosthetic practice that more evidence be found on the efficacy of individual prosthetic components (British Society of Rehabilitation Medicine 2003).

8.5 Limitations

There are several limitations which can be reported relating to this piece of work. A number of these limitations can be attributed to being unable to gain access to military amputees and clinicians working in the field of prosthetics in the MOD setting. Firstly without being able to access prosthetists working within the MOD I was unable to explore any similarities or differences that might exist between the prosthetic decision making process in the MOD and NHS settings. This comparison would have been important in understanding some of the similarities and differences that veteran amputees reported about their prosthetic care in the MOD and the NHS. Similarly, without this information I was unable compare accounts from clinicians and patients on MOD prosthetic care. Secondly, without being able to access the other clinical groups within the MOD,

physiotherapists and rehabilitation consultants I was unable to explore their role in the prosthetic prescription process to that described by these clinical groups and prosthetists based in the NHS in Scotland. Thirdly, being able to access military amputees with the assistance of the MOD would have enhanced the depth and range of participants which took part in the study. I would have been able to use a purposive sampling strategy in order to explore the experiences of different ranks of military amputees with respect to their prosthetic care in the MOD.

There were limitations in the range of participants that I was able to recruit to study two. I had no female or upper limb amputee participants despite neither of these groups being excluded from taking part in the study. This meant that there are issues around the generalisability of the findings of study two to the female and upper limb amputee populations. This limitation could perhaps have been overcome if a larger number of participants had been recruited to study two, however, there were continued issues with recruiting amputee participants to this study. Other ethnic groups were also under represented in the participant sample in study two, this could in part have been due to the exclusion of non-English speaking participants. It is possible that if non-English speaking participants had been included that there would have been differences in their accounts of the prosthetic care that they had received. This again raises issues around the generalisability of the findings of study two to non-English speaking amputee populations in the UK. The generalisability of the findings of study two could also be questioned when considering the relatively small sample size. A larger sample size and wider sampling within Scotland and England would have been beneficial in study two in order to explore more thoroughly the possible differences in patient experience between England and Scotland and possibly even to include participants from Wales and Northern Ireland.

In addition, not all participants within the veteran group received their prosthetic care in Scotland. In response to difficulties in recruiting to this group in Scotland alone, recruitment was opened up to those receiving prosthetic care in England as well. Funding structures for veteran amputees differ between Scotland and England, therefore the participants in this group were talking about services which may not be considered comparable. In addition, not all of the members of patient cohorts met the eligibility criteria, this occurred as it was the participating DSCs who screened for eligibility. This research has highlighted the importance of the long term relationship between the prosthetist and patient; further research might employ a longitudinal design in order to explore the evolution of this relationship over time. A longitudinal design in the current

study would have facilitated following the prosthetic rehabilitation of patients over time and explored their changing experiences of their prosthetic care. However, due to restrictions of time I was unable to use this sort of design. A longitudinal design would also have been able to capture changes in the maturation of the policies implemented during the course of this research.

8.5.1 Recommendations for practice

- Mode of amputation should be taken into consideration during prosthetic rehabilitation of trauma amputees beyond their physical presentation.
- Prosthetists should have access to other prosthetists' experiences of working with different components beyond those working in their own DSC.
- Where possible trauma amputees should be rehabilitated with other trauma amputees.
- The MOD should make patient notes easily accessible to the NHS during the transition of amputees from the MOD to NHS setting.
- Implications for prosthetist training
 - Consideration of further training for prosthetists regarding the psychological effects of amputation
 - Undergraduate prosthetic training should include teaching on the different models of patient involvement and how to incorporate these into their day to day prosthetic practice
 - Training should be provided for prosthetists on how patients can be involved in the decision making process
 - Prosthetists in training should be aware that patients desire for involvement in their care can change over time

8.5.2 Recommendations for policy

- Consideration should be given to the revision of prosthetic rehabilitation guidelines around the difference in the role of the prosthetist in the prosthetic prescription process between Scotland and England.

8.5.3 Recommendations for future research

- These findings suggest further research using a prescriptive decision making approach with the aim to develop a decision making tool to encourage prosthetists to use a more systematic, less intuitive, approach to prosthetic prescription. This would make the decision making process more transparent, in turn assisting in the justification of prescription choices.

- Further research to explore the interaction of amputee patients with prosthetic services is indicated to better understand if this a national change and how best to accommodate consumerism into prosthetic services in the future.
- More research is required to fully understand the development of the relationship between the prosthetist and the patient and the effect that this has in prosthetic care delivery
- Research into the efficacy of SOTA components provided through the NHS as a result of additional funding from recommendations in the Murrison report (Murrison 2011) possibly using n of 1 trial approach.

8.5.4 Recommendations

- Further research is required to understand the prescription processed used by clinicians working within prosthetic care delivery in the MOD.
- Further work is needed to produce prescription guidelines for the use of SOTA prosthetic components within the NHS setting to ensure equity of prosthetic care across Scottish NHS prosthetic services.
- Research is needed to further explore the continuity of prosthetic care within the MOD setting.
- Longitudinal research is needed to further explore military amputees' experience of prosthetic care in the MOD and their subsequent experiences of prosthetic care in the NHS.

8.6 Final thought

Prosthetists role in providing prostheses that meet the needs of those amputees whose lives have been changed through trauma is essential for a number of reasons. The stories of the amputees included in this thesis show that the circumstances which have led to their amputation can have a lasting effect on their rehabilitation journey. Those who have lost a limb through trauma, whether in a civilian or military setting, have experienced a unique set of experiences which can greatly impact the way they view their amputation and associated disability as well as the way that they interact with those clinicians who are involved in their prosthetic rehabilitation. The effect that these unique experiences can have suggest that prosthetists and other clinicians involved in the care of trauma amputees should be aware of the circumstances which led to their amputation and take that into account in the rehabilitation process. This thesis has also shown the

importance of the evolving relationship between trauma amputees and their prosthetists and the benefits that were seen by both groups from developing a good relationship and the impact that this could have on the prosthetic prescription process. Through these developing relationships combined with communication between prosthetists and patients, these groups can work together to create optimal prosthetic prescriptions. Clinical experience and communication are key in enabling prosthetists to prescribe limbs which allow patients to achieve their goals and aspirations in their post amputation lives.

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Appendices

Appendix 1

Original project protocol

Background/Justification

Despite its importance, little research evidence is available to inform prosthetic decision making. Currently, the majority of prosthetic research is focussed upon the technical aspects of prosthetics, for example casting and computer aided design (CAD) techniques and the specifics of prosthetic component design. While the development of new components and prosthetic design are prolific, there is a recognised lack of high quality research on the efficacy of individual components. For these reasons it is recognised within the profession that clinical experience and craft knowledge plays a major role in the prescription of devices. This was highlighted by Hafner, (2005) when he concluded that scientific literature in prosthetics seems to support clinical experience rather than to affect clinical conclusions. Van der Linde et al., (2005) also identified that prosthetic prescription is mainly based on the experiential knowledge of the prescriber. In addition, no research has been carried out into clinicians' decision making practices in prosthetic care.

To date no research has been carried out to compare the prosthetic care provided to servicemen by the MOD with NHS prosthetic provision for veterans and civilians, or to explore the impact on the care experienced by servicemen who are transferred between MOD and NHS services. Additionally, while some research has been carried out into both military and civilian patients' satisfaction with their prostheses, no research to date has examined prosthetic patients' involvement in decision making, how their values and preferences are taken into account in the prescription process, and how this might impact on their quality of life post amputation.

A recent call has been made for the commissioning of the long term outcomes of veterans suffering limb loss as a result of military service (Department of Health, 2011).

Aims

Provision of appropriate prostheses is essential to the wellbeing of patients as they have the potential to enhance or inhibit the patients' sense of self, their ability to achieve what they hope to, their physical function and personal goals. Prosthetists must consider many aspects of care; the prosthetic components and materials which are available as well as what is suitable for the patient, the patients' past and desired future level of activity, knowledge of what can realistically be achieved after rehabilitation, cost and availability of products.

Research Questions

1. What factors (clinical and non-clinical) influence clinical decision making in prosthetic care for civilian amputees and for service attributable amputees?
2. What problems are unique to the decision making process in prosthetics for those serving in the military compared to civilian amputees?

Version 1. 20/08/12

3. What are patients' experiences of prosthetic care in the UK?
4. What are the experiences of involvement in decision making of service attributable amputees?
5. What are the experiences of transition of prosthetic care of those amputees moving from MOD to NHS care?

Method

The project will comprise two studies:

Study 1 will focus on the decision making of clinicians involved in prosthetic prescription in the UK; these include prosthetists and rehabilitation consultants. It will identify the factors these clinicians use when prescribing prostheses. The target group will consist of prosthetists and rehabilitation consultants working within the NHS in Scotland and those working within the Ministry of Defence at the Defence Medical Rehabilitation Centre, Headley Court. Semi-structured interviews will be employed with these two target groups.

Study 2 will comprise three target groups, non-discharged military amputees, veteran amputees now receiving prosthetic care through the NHS and civilian traumatic amputees receiving prosthetic care through the NHS. The study will employ semi-structured interviews with individual members of each target group in order to explore their experience and involvement in the prosthetic care that they have received in either the NHS or Ministry of Defence setting. In the veteran amputee group we will also focus on the experience of the transition of care from the Ministry of Defence to the NHS.

Design

Study 1:

Individual semi-structured interviews will be carried out with prosthetists and rehabilitation consultants involved in the care of prosthetic patients. Critical Incident Technique will be used in these interviews in order to illicit the main factors that clinicians use when making prosthetic prescription choices.

Study 2:

Semi-structured interviews will be carried out with participants from each of three target patient groups to gain an understanding of their experiences of prosthetic care and their involvement in that care and the prosthetic prescription process in the NHS and/or the Ministry of Defence setting.

Setting and Sample

Study 1:

This study will include clinicians from two organisations who provide prosthetic care within the UK, the Ministry of Defence (MOD) and the NHS. The MOD currently provides prosthetic care to injured military personnel at one site in the UK at the Defence Medical Rehabilitation Centre (DMRC) at Headley Court in Epsom. In this setting, prosthetic services are provided by one of the private prosthetic contractors operating in the UK. In Scotland, prosthetic services are provided directly by

the NHS through five limb fitting centres geographically distributed throughout Scotland. Initially three of the larger limb fitting centres in Scotland will be targeted as well as Headley Court to sample prosthetists and rehabilitation consultants working in the MOD and the NHS in Scotland. Scotland will be targeted because the prosthetic services are all delivered through in house NHS services. This differs from the prosthetic services in the rest of the UK which are provided by a mixture of in house services and private companies contracted to the NHS. The proposed sample will contain five rehabilitation consultants, three NHS and two MOD, and ten prosthetists, with a split of seven prosthetists working in the NHS in Scotland and three working within the MOD. Purposive sampling techniques will be employed in order to achieve as diverse a range of perspectives as possible.

Study 2:

The setting for study 2 will be the NHS and MOD as described above and in addition veterans from recent conflicts associated with The British Limbless Ex-Servicemen's Association (BLESMA) the national charity for limbless serving and ex-service men and women and their dependants and widows.

This study contains three participant groups:-

1. Civilians who have undergone amputation as a result of trauma and who have only ever received prosthetic care from the NHS
2. Veterans who have undergone major limb amputation as a result of military service and who have since been discharged from the Services.
3. Members of the army who have lost limb/limbs as a result of service but who have not yet been discharged from Service.

The target sample will be four participants from each of the identified groups providing a total of 12 amputees. The final decision on sample will be dependent upon approval for access from the Ministry of Defence Surgeon General. If permission is not granted for access to serving military amputees then the sample of veteran amputees will be correspondingly increased.

Recruitment and Consent

Study 1:

NHS: The lead prosthetist at each participating limb fitting centre will facilitate recruitment within their centres. Prosthetists and rehabilitation consultants in each of the participating limb fitting centre in Scotland will be sent a letter and information sheet about the study via email or by post to their workplace. They will then be contacted a week later to find out if they would like to participate in the study and, if so, to arrange a single interview at a mutually convenient time and location. Written consent will be obtained by the researcher on the day of the interview.

Ministry of Defence: The final specific method of access to prosthetists and rehabilitation consultants working at Headley Court requires further correspondence and consultation with the Ministry of Defence and will be informed by further discussion with the Commanding Officer at Headley Court once permission for access has been agreed. The anticipated recruitment method is

as follows; the Commanding Officer at Headley Court will distribute information sheets and letters of invitation to each of the prosthetists and rehabilitation consultants working at Headley Court. The information sheet will contain a reply slip which they can complete and return to the researcher by post to indicate if they would like to participate in the study. The return slip will have space for them to fill in their phone number and email address so that the researcher is able to contact the potential participant to organise a mutually convenient time and location for the interview. Written consent will be obtained by the researcher on the day of the interview.

Study 2:

1. Civilian amputees will be recruited through the participating three limb fitting centres in Scotland. The lead prosthetist at each of these centres will be asked to identify likely eligible participants from their patient list based on the inclusion and exclusion criteria outlined. Clinicians will be asked to pay special attention to any diagnosis of PTSD or other mental health problems associated with their trauma identified in their patient notes. They will then be asked to send out a covering letter and information sheet about the study prepared by the researcher to those eligible to participate. The information sheet will contain a reply slip which they can complete and return to the researcher by post to indicate if they would like to participate in the study. The return slip will have space for them to fill in their phone number and email address so that the researcher is able to contact the potential participant to organise a mutually convenient time and location for the interview. Written consent will be obtained by the researcher on the day of the interview.

2. Veteran amputees will be recruited through The British Limbless Ex-Servicemen's Association (BLESMA). A covering letter and information sheet about the study will be sent by BLESMA using their member contact list to those eligible to take part in the study (using the pre-defined set of inclusion and exclusion criteria outlined). The information sheet will contain a reply slip which they can complete and return to the researcher by post to indicate if they would like to participate in the study. The return slip will have space for them to fill in their phone number email address so that the researcher is able to contact the potential participant to organise a mutually convenient time and location for the interview. Written consent will be obtained by the researcher on the day of the interview.

3. The final specific method of access to serving military amputees requires further correspondence and consultation with the Ministry of Defence and will be informed by further discussion with the Commanding Officer at Headley Court once permission for access has been agreed. The anticipated recruitment method is as follows; information sheets and letters of invitation will be disseminated to the prosthetists at Headley Court for them to distribute to eligible patients (as outlined in the inclusion/exclusion criteria). Clinicians will be asked to pay special attention to any diagnosis of PTSD or other mental health problems associated with their trauma identified in their patient notes. The letter of invitation will include a reply slip and the address of the chief investigator which they can use to indicate their desire to participate. The researcher will then contact the possible participant by email to arrange a suitable date and location to carry out the interview.

Data Collection

Study 1:

Version 1. 20/08/12

NHS Clinician Interviews: Semi-structured interviews using Critical Incident Technique will be carried out at a mutually convenient time and location agreed with clinicians in advance. The interview will last for no longer than one hour. Clinician will be asked to recall one or two cases where the prescription of the prosthesis was particularly difficult as well as one or two cases where the prosthetic prescription was straight forward and to recount the outcome in prescription and rehabilitation for those cases. The technique uses 'what' type of questions rather than 'why' and this lessens the possibility of self-justifying bias. Those clinicians who have been involved in the prosthetic care of recently discharged military amputees will also be asked about their experience of the transition of care of these patients from the Ministry of Defence to the NHS.

Study 2:

Interviews with amputees: Semi-structured in depth interviews will be conducted at a mutually convenient time and location agreed with these participants in advance. The interview will last for no longer than one hour. The first part of the interview will focus on their injury and the prostheses they have been provided with and the second part of the interview will focus on their involvement in their prosthetic care. The topic guide is indicative and will be further informed by data gathered in study 1.

All interviews will be audio recorded with consent from participants and transcribed for analysis.

Data Analysis

Framework analysis involves identifying a series of main themes which can then be subdivided into sub-themes or related topics within the theme (subtopics). The approach involves developing a hierarchical thematic framework that is used to classify and organise data according to key themes, concepts and emergent categories. Each main theme is then charted by completing a matrix or table where each case has its own row and columns represent the subtopics. Cells contain relevant summaries from the data set (including indexing to the original transcript). These charts are used to examine the data for patterns and connections. The method has 5 distinct phases that are interlinked (familiarisation, identifying a thematic framework, indexing, charting and mapping and interpretation)

The first three stages of this process are similar to thematic coding of the data. The charting process involves creating charts for key subject areas. Then, for each individual case, characteristics or dimensions related to that subject area can be mapped out (for example, medication taking behaviour, perceptions of medications, previous experience of medications). A whole set of key subject areas can then be easily reviewed for each individual case. Charting involves abstraction and synthesis of the indexed data i.e. the respondent's view or experience in a particular area is summarised by the analyst and entered on the chart and the original text is referenced so that the source can then be traced for data retrieval or verification purposes.

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Appendix 2

Table of changes to original research protocol

	Change made to original protocol	Reason for change	What it contribute to the project
1.	Addition of an alternative participant sample in study one of prosthetic budget holders.	This sample group has been added due to the loss of Ministry of Defence prosthetists and rehabilitation consultants which would have enabled a comparison of prosthetic decision making process in the NHS and MOD to be carried out.	The addition of the sample of prosthetic service budget holders was designed to add to the understanding of the process of prosthetic prescriptions by clinicians in the NHS with an added understanding of the constraints on the process from an organisational point of view.
2.	Increase in the size of civilian amputee and amputee veteran cohorts.	These numbers in these participant groups had to be increased in order to counteract the loss of the serving military amputee population.	The increase in size of these cohorts allowed the research team to compensate for the loss of the military patient population.
3.	Addition of a further participant sample of NHS physiotherapists involved in the rehabilitation of amputees for study one.	Data gathered during interviews with both prosthetists and rehabilitation consultants indicated that physiotherapists are more involved in the process of prosthetic prescription than was initially thought.	By adding a cohort of physiotherapists and interviewing them about their involvement in the prosthetic prescription process. The research team were then able to explore if they also felt involved in this process and if they felt that they were then in what capacity they were involved.
4.	Changed from recruiting the amputee veteran cohort through BLESMA and instead changed the protocol to recruit them through the NHS.	While initially BLESMA had been keen to help with recruitment of this cohort of patients the research team struggled to get this operationalised.	This enabled the research team to access veteran amputees who were accessing NHS prosthetic services in the same way that civilian patients do.
5.	Linked to the change above the research team added a further study site in Preston.	Recruiting this cohort in Scotland proved difficult due to the small number of amputee veterans from recent conflicts being based in Scotland after discharge from the Services. The limb Fitting Centre in Preston is one of the nominated specialist centres for veteran amputees as recommended in the Murrison report and they have an accessible cohort of suitable patients.	This change allowed the research team to have access to a much larger group of appropriate participants thus enabling them to reach their sampling goals.

6.	Changing the method of data collection from face to face interviews to telephone for participants based in England.	Amputee veterans had been a very hard group to recruit and with the majority of this group being recruited through the limb fitting centre in Preston and more than that based in a variety of locations in England it made sense from a logistical point of view to carry out these interviews over the telephone.	This allowed the remainder of the data collection to be completed in a shorter period of time as the timescale for the project reached its end.
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Appendix 3

Participant interview topic guides

NHS Service Manager Topic Guide

1. What do you feel is the current impact of veteran amputee with prostheses originally provided by the Defence medical services is?
2. What do you think the impact of these patients will be in the future?
3. Have you seen any surge as a result of the Murrison report of veterans from previous conflicts wanting upgrades?
4. Is there anything you have actively had to do to prepare your service for prosthetic provision for ex-military amputees?
5. How do you feel that the transition of prosthetic care is handled when a patient is discharged from the MoD and comes into the NHS?
6. Is there anything that you feel is of particular benefit or a hindrance in how this transition is handled at present?
 - a. If so what would those be?
7. Is there anything that you feel could be done better?
8. Do you see there to be any barriers or facilitators/benefits to the way things are working at the moment
9. Do you feel that there are things that will have to change in the future?
10. What are your feelings on the pledge that the MOD will continue to pay for the prosthetics they provide once the patient is back in the NHS?
11. How do you feel the specialist centres proposed in the Murrison report will work out in the future?
12. Do you think this plan will be realised?
13. How many military amputees have you seen from recent conflict joining NHS prosthetic care?
14. Do you think that the high cost of prostheses for ex-military patients will have an impact on non-military amputees?
15. If not any actual impact do you think there is a perception of impact?
 - a. From staff?
 - b. From patients?
16. What role do you feel that patients have in prosthetic prescription?

Professor Brian Williams, Director

Unit 13 Scion House • Stirling University Innovation Park • Stirling • FK9 4NF

Tel: +44 (0) 1786 466341

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Study 1: NHS Rehabilitation Consultant Topic Guide

Version 2, 13/08/12

1. For the sake of the tape could you just say what your job title is within the hospital is and the remit of your job?
2. Would you be in charge of all amputees who come through WestMARC or do you have someone else working in the same kind of role?
3. Who makes the decision to amputate?
4. What assessments would be carried out to determine that this is the right course of action?
5. What would be the first meet a patient who was undergoing or had undergone an amputation?
6. What would your role at that stage be?
7. Would you see all amputees or just specific cases?
8. Do you carry out any of the amputations?
9. Do you have any say in if a patient will or won't be a limb wearer?
10. Who makes the decision on who will be a limb wearer and who won't?
11. What are the factors that affect this decision?
12. Would you be part of an MDT working with that patient?
13. What sort of an impact do you feel that you have on any aspects of prosthetic prescription?
14. How closely do you feel you work with prosthetists and physiotherapists on amputee patients?
15. Have you had any experience of working with ex-military patients in the prosthetic setting?

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Professor Brian Williams, Director

Unit 13 Scion House • Stirling University Innovation Park • Stirling • FK9 4NF

Tel: +44 (0) 1786 466341

www.nmahp-ru.ac.uk

16. What sort of a role would you play in prosthetic prescription?
17. Can you think of any cases where there has been conflict within the MDT regarding a patient's prosthetic prescription?
18. Can you think of any specific cases where prosthetic fitting has been difficult and maybe talk me through that process?

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Glasgow Caledonian University is a charity registered in Scotland, number SC 021474*

Professor Brian Williams, Director

Unit 13 Scion House • Stirling University Innovation Park • Stirling • FK9 4NF

Tel: +44 (0) 1796 466341

www.nmahp-ru.ac.uk

Study 1: NHS Physiotherapist Topic Guide

Version 2, 13/08/12

1. What would your role in the prosthetic rehabilitation of amputees be?
2. How early in this process would you begin to be involved?
3. What assessments would you carry out to determine if someone will be a limb wearer or not?
4. Who makes the decision on who will be a limb wearer and who won't?
5. What are the factors that affect this decision?
6. What assessments would you carry out that could have a direct or indirect effect on prosthetic fitting?
7. Would you be part of an MDT working with that patient?
8. What sort of an impact do you feel that you have on any aspects of prosthetic prescription?
9. How closely do you feel you work with prosthetists on amputee patients?
10. Have you had any experience of working with ex-military patients in the prosthetic setting?
11. Can you think of any specific cases where your input has been sought for prosthetic prescription?
12. Can you think of any cases where there has been conflict within the MDT regarding a patient's prosthetic prescription?

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Glasgow Caledonian University is a charity registered in Scotland, number SC 021474*

Professor Brian Williams, Director

Iris Murdoch Building • University of Stirling • Stirling • FK9 4LA

Tel: +44 (0) 1786 466341 • Fax: +44 (0) 1786 466100

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Study 2: NHS Patient Interview Schedule

Version 2, 13/05/12

I am a Doctoral student at the University of Stirling working within the NMAHP research unit. By background I am a trained prosthetist and as part of my PhD I am undertaking a study to look into clinicians decision making in prosthetic prescription and patients experience of prosthetic care and in particular your thoughts and experiences of your involvement in the prosthetic decision making process.

1. Can you tell me a little bit about yourself?

- How old are you?
- When did you lose your limb?
- How did you lose your limb/limbs?
- Where do you receive prosthetic treatment?
- Is this the prosthetic centre that you have always attended? (if not then where have you been treated previously?)

2. In general how do you feel about the prosthetic care that you have received?

- How often would you generally see your prosthetist/consultant?
- Would this be through a process of routine review appointments?
- Are you satisfied in general with the prosthetic care that you receive?
- Do you feel that there is anything that could have been done better?

3. Who has been involved in your prosthetic care and rehabilitation?

4. How involved do you feel you've been in the process of deciding what sort of limb you get?

- Did you think that this level of involvement was enough/not enough?
- Did you have a chance to talk to your prosthetist/consultant about what you wanted?
- Do you feel that your views were taken into account?
- Did they talk to you about what type of limb you were going to get?
- Did they talk to you about what you might be able to do/or not be able to do with the limb?

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Professor Brian Williams, Director

Iris Murdoch Building • University of Stirling • Stirling • FK9 4LA

Tel: +44 (0) 1786 466341 • Fax: +44 (0) 1786 466100

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5. Would there be anyone out with the rehabilitation team that you would discuss your prosthetic care with?

- I.e. discussing aspirations/hopes with family members or friends?
- Would you ever take anyone with you to a prosthetic appointment?

6. How many limbs have you been provided with?

- Do you have any activity limbs?
- What is the process you have to go through to get additional limbs?
- Do you feel that you are able to achieve all that you would like to achieve with the prosthetic limbs you have?

7. Did your prosthetist ask you what you hoped to be able to achieve after being fitted with your limb?

- Do you feel that they took into account what you said?
- If so, in what way?
- If not, was it explained why this was the case?

8. What has been your overall experience of the prosthetic services that are available to you?

- Is there anything that you feel is particularly good about the service you receive?
- Is there anything in particular that you feel could be better?

9. Are there any other issues that you would like to talk about?

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Nursing, Midwifery and Allied Health Professions Research Unit

Professor Brian Williams, Director

Iris Murdoch Building • University of Stirling • Stirling • FK9 4LA

Tel: +44 (0) 1786 466341 • Fax: +44 (0) 1786 466100

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Study 2: Amputee Veteran Interview Schedule

Version 2, 13/08/12

I am a Doctoral student at the University of Stirling working within the NMAHP research unit. By background I am a trained prosthetist and as part of my PhD I am undertaking a study to look into clinicians decision making in prosthetic prescription and patients experience of prosthetic care and in particular your thoughts and experiences of your involvement in the prosthetic decision making process.

1. Can you tell me a little bit about yourself?

- When did you lose your limb?
- How did you lose your limb/limbs?
- Did you lose your limb at the time of injury or did you have it amputated at a later date?
- Have you ever had to have any revision surgery?
- How long ago were you discharged from the military?

2. Looking back to before you were discharged, in general how do you feel about the prosthetic care that you received from the Ministry of Defence?

- Do you feel that there is anything that could have been done better?

3. Who was involved in your prosthetic care and rehabilitation at that time?

4. How involved did you feel you've been in the process of deciding what sort of limb you got?

- Did you think that this level of involvement was enough/not enough?
- Did you have a chance to talk to your prosthetist/consultant about what you wanted?
- Do you feel that your views were taken into account?
- Did they talk to you about what type of limb you were going to get?
- Did they talk to you about what you might be able to do/or not be able to do with the limb?

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Nursing, Midwifery and Allied Health Professions Research Unit

Professor Brian Williams, Director

Iris Murdoch Building • University of Stirling • Stirling • FK9 4LA

Tel: +44 (0) 1786 466341 • Fax: +44 (0) 1786 466100

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- Did you feel that you were able to ask for most of what you wanted?

5. How many limbs were you provided with by the MoD?

- If more than one, what are the other limbs for? (space, different activities etc.)

6. Did your prosthetist ask you what you hoped to be able to achieve after being fitted with your limb?

- Do you feel that they took into account what you said?
- If so, in what way?
- If not, was it explained why this was the case?

7. Now thinking about the prosthetic care you've received in the NHS, in general how do you feel about the prosthetic care that you have received?

- Do you feel that there is anything that could have been done better?
- What were your expectations of NHS prosthetic services before you were discharged from Service?

8. Who has been involved in your prosthetic care and rehabilitation within the NHS?

9. How involved do you feel you've been in the process of deciding what sort of limb you get?

- Did you think that this level of involvement was enough/not enough?
- Did you have a chance to talk to your prosthetist/consultant about what you wanted?
- Do you feel that your views were taken into account?
- Did they talk to you about what type of limb you were going to get?
- Did they talk to you about what you might be able to do/or not be able to do with the limb?

10. Did your prosthetist ask you what you hoped to be able to achieve after being fitted with your limb?

- Do you feel that they took into account what you said?
- If so, in what way?
- If not, was it explained why this was the case?

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Nursing, Midwifery and Allied Health Professions Research Unit

Professor Brian Williams, Director

Irish Murdoch Building • University of Stirling • Stirling • FK9 4LA

Tel: +44 (0) 1786 466341 • Fax: +44 (0) 1786 466100

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11. What has been your overall experience of the prosthetic services that have been available to you?

- Is there anything that you feel is particularly good about the service you receive?
- Is there anything in particular that you feel could be better?

12. Are there any other issues that you would like to talk about?

13. What was your experience of the transition of care from the Ministry of Defence to the NHS?

- Do you feel that there was anything that could have been done differently?
 - If so, what?
- Has there been much noticeable difference in the care that you have received between the MoD and the NHS?
 - If so, what would these be?

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Professor Brian Williams, Director

Iris Murdoch Building • University of Stirling • Stirling • FK9 4LA

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7. Can you think of a time when someone had the choice but didn't want the most expensive – explain the situation

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Professor Brian Williams, Director

Iris Murdoch Building • University of Stirling • Stirling • FK9 4LA

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Study 1: NHS Clinician Interview Topic Guide

Version 1, 27/05/12

Types of cases to be used in the critical incident technique to elicit case factors (Part A) and questions asked about each case (Part B). Additional general questions referring to the transition of prosthetic care between the Ministry of Defence and the NHS (Part C)

Part A

1. Think of a case where you were treating a trauma or military patient while working within the NHS and the prescription choice was very straight forward.
2. Think of a case where you were treating a trauma or military patient while working within the NHS and the prescription choice was very difficult.
3. Think of a case when there was a conflict between those involved in prosthetic prescription of a trauma or military patient
4. Think of a case where you feel like the prescription provided for the patient was maybe not what you would have provided if there were no external constraints

Part B

1. What pieces of information, that is, cues or factors, did you use to make the decision of prosthetic prescription?
2. What were the factors in the case that most strongly led to the decision you made?
3. What other pieces of information influenced your decision? (NB this is most likely where organisational/group/contextual factors, including views of amputees, will be elicited.)
4. What aspects made the prescription choice straight forward/difficult/conflicted?
5. What factors constrained your prescription choice?
6. How do you feel patients are involved in the decision?
7. Are their views actively sought?

Part C

1. How do you feel that the transition of prosthetic care is handled when a patient is discharged from the MoD and comes into the NHS?
2. Is there anything that you feel is of particular benefit or a hindrance in how this transition is handled at present?
 - a. If so what would those be?
3. Is there anything that you feel could be done better?
4. What role do you feel that patients play in the prosthetic decision making process?
5. Is this level appropriate?
6. Should they be involved less or more?

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Appendix 4

Participant Information Sheet (Staff)

<p>Professor Brian Williams, Director</p> <p>Iris Murdoch Building • University of Stirling • Stirling • FK9 4LA</p> <p>Tel: +44 (0) 1786 466341 • Fax: +44 (0) 1786 466100</p> <p>www.nmahp-ru.ac.uk</p> <p>Study 1: NHS Clinician Interview Information Sheet </p> <p>Version 1, 26/08/2013</p> <p>Invitation:</p> <p>My name is Karen Semple and I am undertaking a PhD at the University of Stirling. I am required to undertake a project as part of my course and invite you to take part in the following study. However, before you decide to do so, I need to be sure that you understand firstly why I am doing it, and secondly what it would involve if you agreed. I am therefore providing you with the following information. Please read it carefully and be sure to ask any questions you might have and, if you want, discuss it with others including your friends and family. I will do my best to explain the project to you and to provide you with any further information you may ask for now or later.</p> <p>What is the purpose of the study?</p> <p>Over the last 10 years there has been an increase in the numbers of military personnel losing limbs through service related injuries. The majority of these amputees are initially treated within the Ministry of Defence before being medically discharged from Service and after this point they receive prosthetic care from the NHS. Each year in the NHS a proportion of new amputees are treated for limb loss resulting from trauma such as road traffic accidents. This study will explore amputees' experience of their prosthetic care, whether they are cared for by the NHS or the Ministry of Defence. It will also examine the ways in which clinicians make prosthetic prescription choices. We hope that this will help us to improve the care offered to people who require prostheses in the future.</p> <p>Why have I been chosen?</p> <p>You have been chosen to participate as you are a clinician involved in the rehabilitation of traumatic and/or ex-military amputees.</p> <p>Do I have to take part?</p> <p>No. Taking part in the study is voluntary and it is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and we will ask you for a contact phone number or email address so that we can arrange a suitable time to talk about your experience of working with civilian and/or ex-military amputees. You will be asked to sign a consent form at a later date. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your position in the future.</p> <p><small>NMAHP Research Unit is funded by the Chief Scientist Office, Scottish Government Bases at: Glasgow Caledonian University and University of Stirling</small></p> <p><small>The University of Stirling is a charity registered in Scotland, number SC 011159 Glasgow Caledonian University is a charity registered in Scotland, number SC 021474</small></p>	
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Professor Brian Williams, Director

Iris Murdoch Building • University of Stirling • Stirling • FK9 4LA

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What will happen to me if I do take part?

If you choose to take part in the study a member of the research team will contact you to arrange a time and a mutually convenient location for an interview to take place. The interview will take about 60 minutes. The interviewer will ask you about a number of topics related to your delivery of prosthetic care and in particular the process of decision making you use when making those prescription choices. Your conversation will be tape recorded with your permission, this makes it easier for the researcher to analyse all the interviews carried out at a later date. Only members of the research team will have access to these recordings. Your permission will be requested to use anonymised quotes in publications or presentations. Personal details that may identify participants will not be used in any reports; however, the relatively small number of prosthetists working means that individuals might be identifiable as a result.

Consent:

You will be asked to consent to taking part in an interview with a researcher and to having your conversation tape recorded.

If I agree to take part can I withdraw later from the study?

Yes, you can withdraw at any time. You can withdraw by either telephoning or writing to any member of the research team indicating your desire to withdraw. Contact details are given at the end of this sheet. Any data collected up to that point (tape recordings or written versions of your interview) will be destroyed in a safe and secure manner.

Are there any disadvantages to taking part?

We do not think that there are any disadvantages to taking part in this study.

What are the possible benefits of taking part?

There is no benefit for you specifically as a result of taking part in the study but we hope the study will continue to improve prosthetic services in the future. You will be reimbursed for any reasonable travel expenses and given a £10 voucher to say thank you for your time.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with the research prosthetist, Karen Semple, who is the Chief Investigator responsible for the study or Professor William Lauder who is the external contact for this study. Please see contact details at the end of this sheet.

What are my rights?

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Professor Brian Williams, Director

Iris Murdoch Building • University of Stirling • Stirling • FK9 4LA

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If you would like to pursue a complaint through the University of Stirling who are acting as the research sponsor details about this are available from the research team. Also as an employee of the NHS, you have the right to pursue a complaint through the usual NHS employee process. Note that the NHS has no legal liability for non-negligent harm. However, if you are harmed and this is due to someone's negligence, you may have grounds for a legal action against the NHS but you may have to pay your legal costs.

If you would like to speak to someone who knows about this study who is an independent advisor or if you remain unhappy and wish to complain formally please contact:

Professor William Lauder
School of Nursing, Midwifery and Health
University of Stirling
Stirling, FK9 4LA
Tel: 01786 466345
Fax: 01786 466333
Email: William.lauder@stir.ac.uk

It will simplify the complaint process if you have saved this sheet of paper and any consent form you signed and can provide the name of the study and the study number listed at the top of this form when making a complaint.

Will my taking part in this study be kept confidential?

All the information we collect both tape recordings and written transcripts will be treated as strictly confidential in accordance with the Data Protection Act 1998. The tape recordings and written record of your interview will be kept for 10 years and will not show your name. They will be kept in locked filing cabinets on secure premises at The University of Stirling and would only be accessible to the study team.

The data collected will be used for the study only. Only selected members of the study team will have access to your information. The tape recording and written record of your interview will be securely stored for a maximum of 10 years after the end of the study and will then be destroyed. The researchers will take all reasonable steps to protect your privacy.

Will there be any attempts to contact me after the study is complete?

No

What will happen to the results of the research study?

Once the study has been completed the information will be analysed and a report will be written for our funders. In addition to this, the study will be reported in academic

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Professor Brian Williams, Director

Iris Murdoch Building • University of Stirling • Stirling • FK9 4LA

Tel: +44 (0) 1786 466341 • Fax: +44 (0) 1786 466100

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and may also be presented at conferences for prosthetists, other health professionals and researchers. Your own personal information will not be identified in any reports we write. It will not be possible for you to be identified through our reporting of the findings.

Who is organising and funding the research?

The research is being carried out by

The Nursing, Midwifery and Allied Health Professions (NMAHP) Research Unit University of Stirling, Stirling FK9 4LA

The research has been funded by

The Nursing, Midwifery and Allied Health Professions Research Unit
University of Stirling
Stirling
FK9 4LA

The State of the Art Prosthetics (SOTA) Group
Smart Centre
Astley Ainslie Hospital
133 Grange Loan
Edinburgh
EH9 2HL

Who has reviewed the study?

The East of Scotland Research Ethics Committee 1, which has responsibility for scrutinising proposals for medical research on humans, has examined the proposal and has raised no objections from the point of view of medical research ethics. It is a requirement that your records in this research, together with any relevant records, be made available for scrutiny by monitors from University of Stirling and NHS Tayside, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

Thank you for taking the time to read this Information Sheet and for considering taking part in this study.

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Professor Brian Williams, Director

Iris Murdoch Building • University of Stirling • Stirling • FK9 4LA

Tel: +44 (0) 1786 466341 • Fax: +44 (0) 1786 466100

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If you have any questions please contact Karen Semple or Dr Helen Cheyne at the address below

NMAHP Research Unit

Iris Murdoch Building

University of Stirling

Stirling

FK9 4LA

Tel: 01786 466101

Email: karen.semple@stir.ac.uk or h.l.cheyne@stir.ac.uk

Please take time to think about this. If you would like to take part please fill in the attached form and return it to me using the attached envelope within 1 week.

✂-----

I am interested in being involved in the study and I am happy to be contacted about participating.

Name:

Email address:

Telephone number:

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Appendix 5

Recruitment website screenshot

http://www.veteran-amputee-study.co.uk/

Home Favorites Tools Help

File - Outlook We... My Exercise Log RefGrab-It bookmarklet Suggested Sites Web Slice Gallery

Veteran Amputee Study Invitation - Have your say about your care

Project Information

Over the last 10 years there has been an increase in the numbers of military personnel losing limbs through service related injuries. The majority of these amputees are treated initially within the Ministry of Defence before being medically discharged from Service. From this point prosthetic (limb fitting care) for these patients is delivered by the NHS. Currently little is known about how these organisations compare in their delivery of prosthetic care. The aims of this research study is to explore these potential differences in care by speaking to amputee veterans about their experiences of limb fitting services in the Ministry of Defence and the NHS and their experiences of moving from one organisation to the other. So if you are a veteran who has lost a limb we would like to speak to you. The findings from this study will be given to each of these organisations for their information and consideration.

Can I take part and what do I need to do?

If you would like to take part then have a look at the criteria you should meet to do so.

If you think you are eligible and you would like to participate please contact the researcher using the details below. If your eligibility is confirmed then you will be asked to take part in a one off, one on one, hour long interview with the researcher which can either be done in person or over the phone. All information and data gathered will be anonymised so that none of the participants can be identified.

Participant Criteria

1. Are you living in the UK?
2. Did you lose your limb/limbs during military service?
3. Is it less than 10 years since your amputation?
4. Are you between the ages of 18-84?
5. Are you now receiving prosthetic care through the NHS?

About the researcher

I am a prosthetist by training and I am currently doing my PhD at the University of Stirling in the NMAHP Research Unit. I want to hear your experiences of prosthetic care in the UK within the military and the NHS.

For more information on the study or if you wish to participate please use one of the contact methods below:-

Tel: 01786 458101
Email: Karen.samp@stir.ac.uk
Address: NMAHP Research Unit
Unit 12 Scott House
Stirling University Innovation Park
Stirling
FK9 4LP
Twitter: @Karen_Samp04

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Appendix 6

Response from the School of Health Sciences Research Ethics Committee

JP/SG

11 July 2012

Karen Semple
PhD Student
NMAHP Research Unit
Iris Murdoch Building
University of Stirling
Stirling
FK9 4LA



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AND HEALTH

Email: nursingmidwifery@stir.ac.uk
Web: www.nm.stir.ac.uk

John Paley
Chair
School Research Ethics Committee

School of Nursing, Midwifery and Health
University of Stirling
Stirling FK9 4LA

Tel: +44 (0) 1786 466399
Fax: +44 (0) 1786 466333
Email: john.paley@stir.ac.uk

Dear Karen

Factors affecting clinical decision making in prosthetic prescription

Thank you for submitting your proposal to SREC. As you are aware, it was discussed at the meeting on Wednesday 11 July 2012. We are grateful that you were able to attend the meeting, and that you answered our questions with such disarming honesty.

As I suggested to you at the time, we don't feel that we can give full approval yet, in anticipation of a bit more information and some clarification. However, we don't think it necessary to invite you to resubmit the proposal to the next meeting, particularly as that won't be till September. So the matter will be handled on a chair's action basis.

The additional points and queries are as follows (there is nothing over and above what we discussed with you at the meeting).

- a) If you are successful in securing access to Headley Court, and in obtaining both the necessary permissions and the approval of the military REC, we would need written confirmation of this, together with notification of any resulting amendments to the protocol.
- b) We think it vital to add to the list of exclusion criteria reference to the mental state of eligible people. For example, some of those who experience traumatic injury subsequently suffer from PTSD and related conditions. We assume that such patients would not be included in the study. Consequently, we would ask you to submit a revised list of inclusion and exclusion criteria.

Highland Campus:
Centre for Health Science
Old Perth Road
Inverness IV2 3JH

Tel: +44 (0) 1463 255655
Fax: +44 (0) 1463 255654

Stirling Campus:
Stirling
FK9 4LA

Tel: +44 (0) 1786 466340
Fax: +44 (0) 1786 466333

Western Isles Campus:
Western Isles Hospital
MacAulay Road
Stornoway Isle of Lewis HS1 2AF

Tel: +44 (0) 1851 708243
Fax: +44 (0) 1851 708070

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- c) With the exclusion criteria amended in this way, you would need to ensure that the recruitment procedure could identify people suffering from the kind of mental health condition that would effectively rule out their participation. It is not clear that their own clinicians would have the necessary skills, however well qualified they are in other respects. So we would like you to provide an account of the measures you will take to identify otherwise eligible patients who meet the mental health exclusion criterion (whatever form that takes).
- d) The potential for distress among the participants in this study, especially given the fact that their trauma occurred within the last five years, and you are asking them questions about how they lost their limbs, is obviously considerable. It is far more than the embarrassment referred to at A23. While providing the name and number of an independent person (A6-2) is necessary and welcome, the Committee thinks that more specialised back-up is required. An arrangement which would fit this study, and for which there are precedents in the School, is to supply the name of a qualified person – in this case, someone qualified to counsel people who suffer from trauma-related distress – who has agreed to act in this capacity, should this kind of service be required. We would be grateful if you could let us know the name of such a person, and let us have a copy of a letter in which they agreed to participate in the study.

Sandy McComish, who was lead reader for this application, has a list of minor inconsistencies and typographical errors which he would be prepared to go over with you. This is in the interests of tidying up the application, and is in no sense of a condition or requirement; nevertheless, I would recommend that you contact him to set up a meeting.

Finally, let me reiterate what I said when we discussed the proposal at the meeting. The Committee was very taken with the project, which we find interesting, worthwhile, and potentially exciting. Let me wish you the best of luck with it.

Yours sincerely



John Paley
(Chair)

School of Nursing, Midwifery and Health Research Ethics Committee

Appendix 7

Thematic analysis coding – example

ST06

Factors affecting prosthetic prescription

Who do patients attend with?

Which clinicians would the patient meet first?

Consultants for medical problems / complications

Who ~~is~~ is involved in the prescription process.

Restrictions in prescription

Input from Physios re: transfemoral.

Discussion with them about prescribing certain things.

Match patients aspirations with their needs.

"We try and match the patients' aspirations with their physical need as much as possible." blue pg 3.

Peer support / decision making

Case conferences.

Informal discussion about different patients.

Patients asking for inappropriate components.

Patients doing their own research on components

Explanation for not prescribing components.

- 'no it's not within our budget'.

What is and isn't provided by the NHS.

Justifying prescription choice

- Cost, suitability

Process of transition of care from MAI to NHS.

No protocol

Patients turning up on the doorstep.

More expertise in Glasgow & Edinburgh.

Certified for components (C-leg, Genium etc).

Number of discharged amputee veterans. (Post 911).

Number of limbs these patients have

Upkeep of Veterans prescriptions

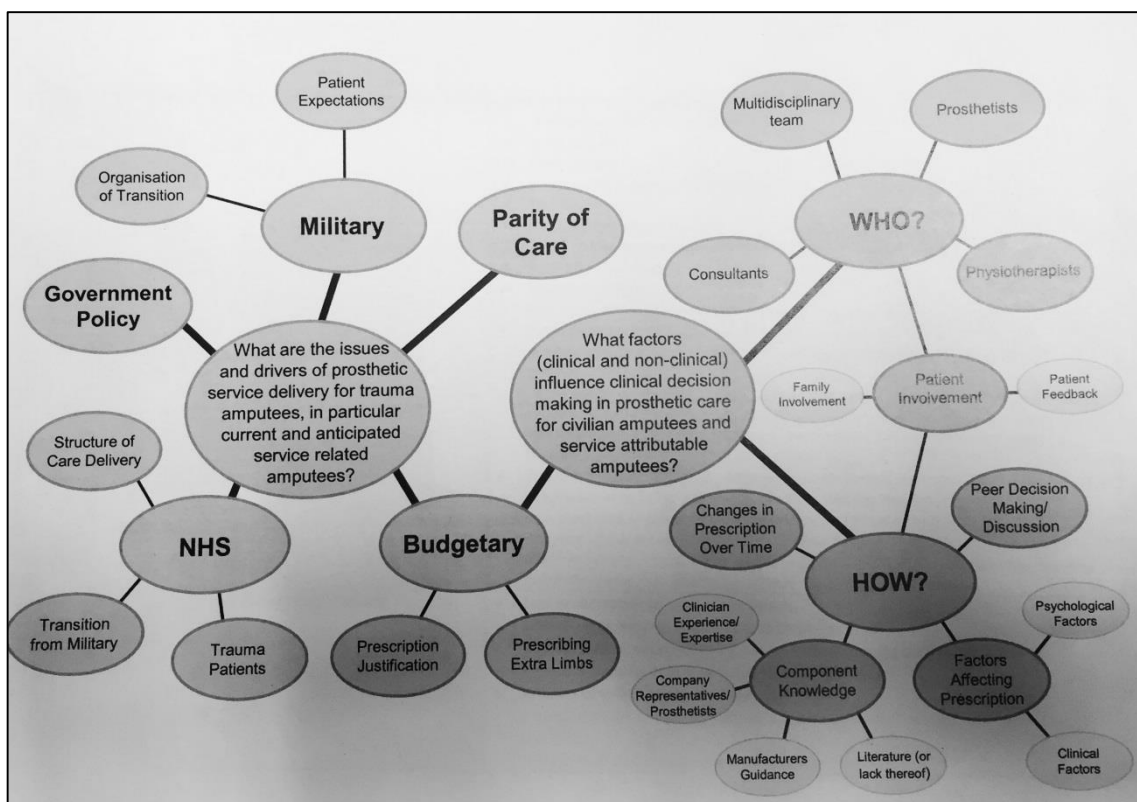
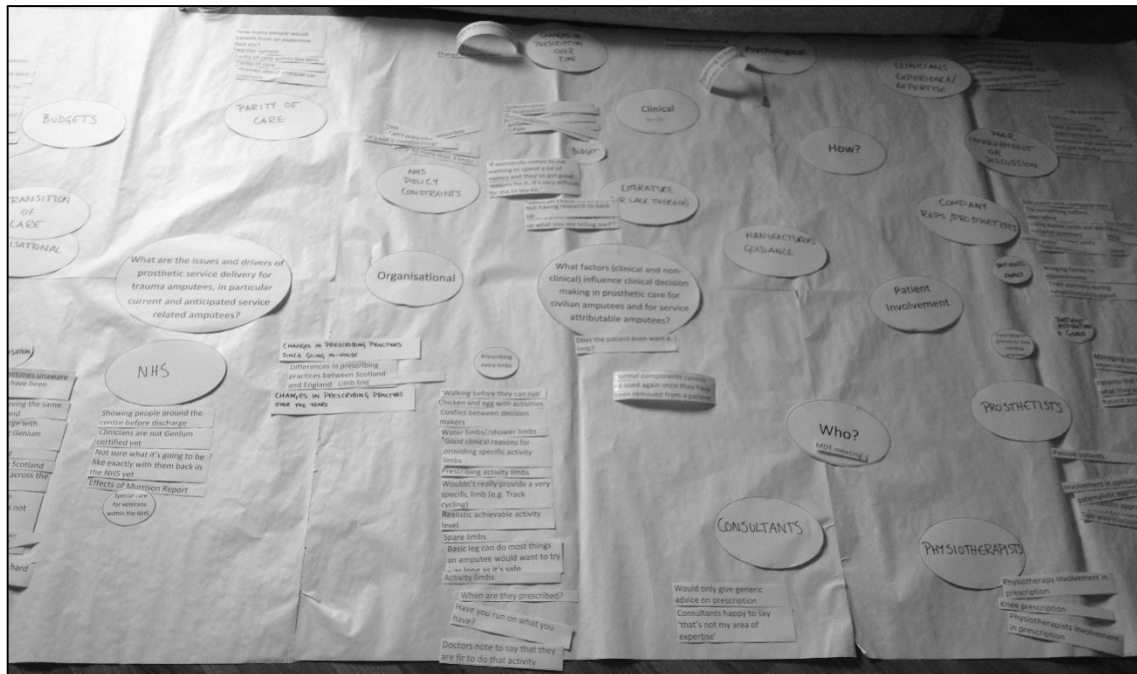
Previous war vets coming forward for better prescriptions.

Concerns of amp vets in the NHS system.

- Management / Monetary
- Time spent with patients for components like the C-leg

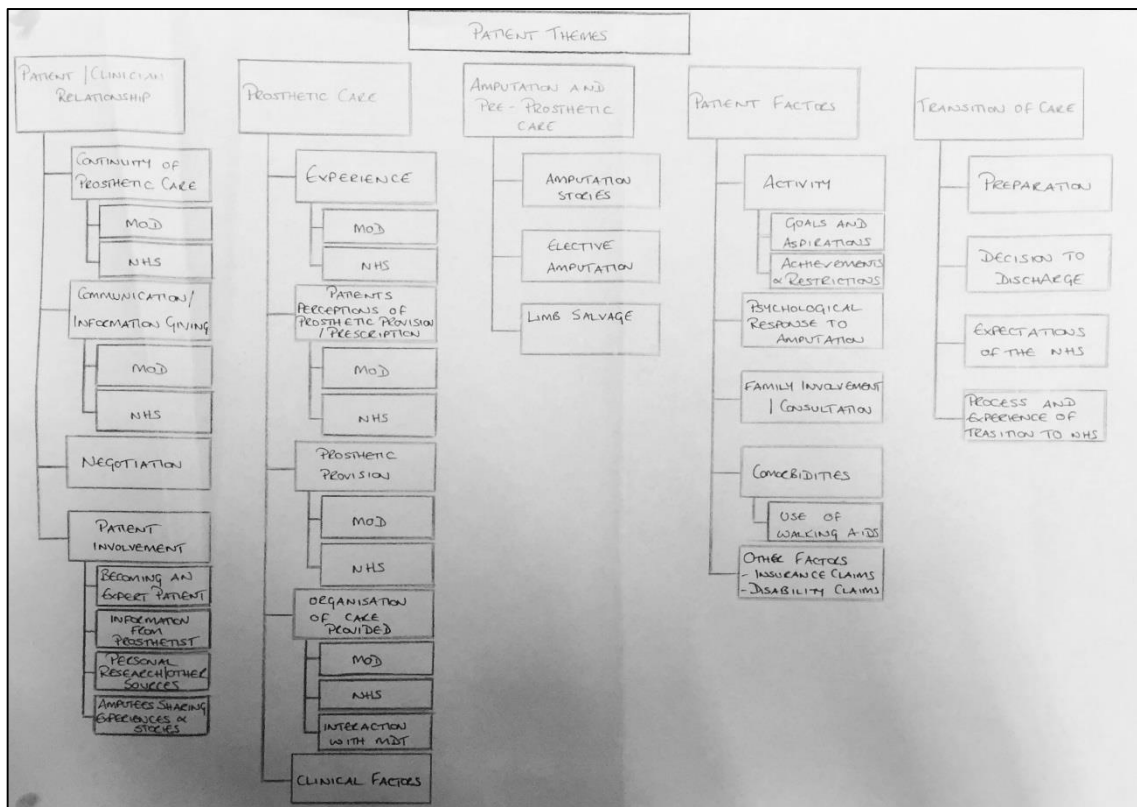
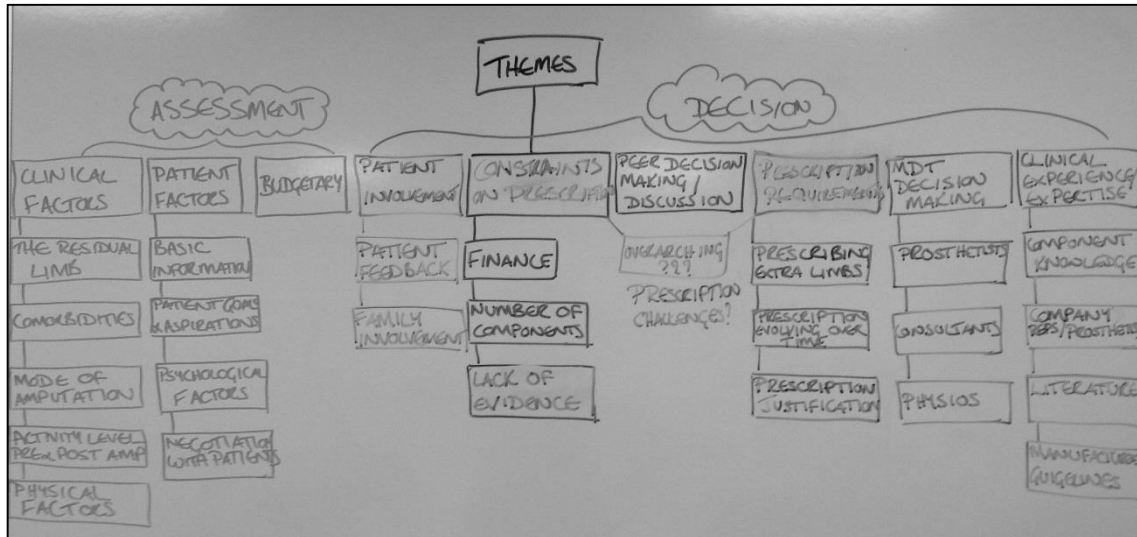
Appendix 8

Thematic analysis: Phase 3 mind maps




Appendix 9

Initial thematic frameworks



Appendix 10

Participant Information Sheet (patient)

					
Professor Brian Williams, Director					
Iris Murdoch Building • University of Stirling • Stirling • FK9 4LA					
Tel: +44 (0) 1786 466341 • Fax: +44 (0) 1786 466100					
www.nmahp-ru.ac.uk					
Study 2: NHS Patient Interview Information Sheet					
		Version 3, 09/10/2012			
Invitation:					
<p>My name is Karen Semple and I am undertaking a PhD at the University of Stirling. I am required to undertake a project as part of my course and invite you to take part in the following study. However, before you decide to do so, I need to be sure that you understand firstly why I am doing it, and secondly what it would involve if you agreed. I am therefore providing you with the following information. Please read it carefully and be sure to ask any questions you might have and, if you want, discuss it with others including your friends and family. I will do my best to explain the project to you and to provide you with any further information you may ask for now or later.</p>					
What is the purpose of the study?					
<p>Over the last 10 years there has been an increase in the numbers of military personnel losing limbs through service related injuries. The majority of these amputees are initially treated within the Ministry of Defence before being medically discharged from Service and after this point they receive prosthetic care from the NHS. Each year in the NHS a proportion of new amputees are treated for limb loss resulting from trauma such as road traffic accidents. This study will explore amputees' experience of their prosthetic care, whether they are cared for by the NHS or the Ministry of Defence. It will also examine the ways in which clinicians make prosthetic prescription choices. We hope that this will help us to improve the care offered to people who require prostheses in the future.</p>					
Why have I been chosen?					
<p>You have been chosen to participate as you have lost a limb or limbs as a result of trauma in the last ten years.</p>					
Do I have to take part?					
<p>No. Taking part in the study is voluntary and it is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and we will ask you for a contact phone number or email address so that we can arrange a suitable time to talk to you about your experiences of prosthetic care. You will be asked to sign a study consent form at a later date. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive now or in the future.</p>					
<p><i>NMAHP Research Unit is funded by the Chief Scientist Office, Scottish Government Bases at: Glasgow Caledonian University and University of Stirling</i></p> <p><i>The University of Stirling is a charity registered in Scotland, number SC 011159 Glasgow Caledonian University is a charity registered in Scotland, number SC 021474</i></p>					

Professor Brian Williams, Director

Iris Murdoch Building • University of Stirling • Stirling • FK9 4LA

Tel: +44 (0) 1798 466341 • Fax: +44 (0) 1798 466100

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What will happen to me if I do take part?

If you choose to take part in the study a member of the research team will contact you to arrange a time for an interview to take place, either in the limb fitting centre or at your home if you prefer. The interview will take about 60 minutes. The interviewer will ask you about a number of topics related to the prosthetic care which you have received and your experience of that care, for example, you will be asked what you liked and disliked about your care and anything you would have wanted or would want to be different in the future. Your conversation will be taped with your permission, this makes it easier for the researcher to analyse all the interviews carried out at a later date. Only members of the research team will have access to these tapes. Your permission will be requested to use anonymised quotes in publications or presentations.

Consent:

You will be asked to consent to taking part in an interview with a researcher and to having your conversation tape recorded.

If I agree to take part can I withdraw later from the study?

Yes, you can withdraw at any time and it will not affect your future medical care. You can withdraw by either telephoning or writing to any member of the research team indicating your desire to withdraw. Contact details are given at the end of this sheet. Any data collected up to that point (tape recordings or written versions of your interview) will be destroyed in a safe and secure manner.

Are there any disadvantages to taking part?

We do not think that there are any disadvantages to taking part in this study.

What are the possible benefits of taking part?

There is no immediate health benefit involved in taking part in the study but we hope the study will continue to improve prosthetic services in the future. You will be reimbursed for any reasonable travel expenses and given a £10 voucher to say thank you for your time.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with the research prosthetist, Karen Semple, who is the Chief Investigator responsible for the study or Professor William Lauder who is the external contact for this study. Please see contact details at the end of this sheet.

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What are my rights?

If you would like to pursue a complaint through the University of Stirling who are acting as the research sponsor details about this are available from the research team. Also as a patient of the NHS, you have the right to pursue a complaint through the usual NHS process. For advice on how to do this you can contact the Patient Advice and Liaison Services at the hospital concerned. Note that the NHS has no legal liability for non-negligent harm. However, if you are harmed and this is due to someone's negligence, you may have grounds for a legal action against the NHS but you may have to pay your legal costs.

If you would like to speak to someone who knows about this study who is an independent advisor or if you remain unhappy and wish to complain formally please contact;

Professor William Lauder
School of Nursing, Midwifery and Health
University of Stirling
Stirling
FK9 4LA
Tel: 01786 466345
Fax: 01786 466333
Email: William.lauder@stir.ac.uk

It will simplify the complaint process if you have saved this sheet of paper and any consent form you signed and can provide the name of the study and the study number listed at the top of this form when making a complaint.

Will my taking part in this study be kept confidential?

All the information we collect both tape recordings and written transcripts will be treated as strictly confidential in accordance with the Data Protection Act 1998. The tape recordings and written record of your interview will be kept for 10 years and will not show your name. They will be kept in locked filing cabinets on secure premises at The University of Stirling and would only be accessible to the study team.

The data collected will be used for the study only. Only selected members of the study team will have access to your information. The tape recording and written record of your interview will be securely stored for a maximum of 10 years after the end of the study and will then be destroyed. The researchers will take all reasonable steps to protect your privacy.

Will there be any attempts to contact me after the study is complete?

No

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What will happen to the results of the research study?

Once the study has been completed the information will be analysed and a report will be written for our funders. In addition to this, the study will be reported in academic journals and may also be presented at conferences for prosthetists, other health professionals and researchers. Your own personal information will not be identified in any reports we write. It will not be possible for you to be identified through our reporting of the findings.

Who is organising and funding the research?

The research is being carried out by

The Nursing, Midwifery and Allied Health Professionals (NMAHP) Research Unit University of Stirling, Stirling, FK9 4LA

The research has been funded by

The Nursing, Midwifery and Allied Health Professions Research Unit
Iris Murdoch Building
University of Stirling
Stirling
FK9 4LA

The State of the Art Prosthetics (SOTA) Group
Smart Centre
Astley Ainslie Hospital
133 Grange Loan
Edinburgh
EH9 2HL

Who has reviewed the study?

The East of Scotland Research Ethics Committee 1, which has responsibility for scrutinising proposals for medical research on humans, has examined the proposal and has raised no objections from the point of view of medical research ethics. It is a requirement that your records in this research, together with any relevant records, be made available for scrutiny by monitors from University of Stirling and NHS Tayside, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

Thank you for taking the time to read this Information Sheet and for considering taking part in this study.

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Professor Brian Williams, Director

Iris Murdoch Building • University of Stirling • Stirling • FK9 4LA

Tel: +44 (0) 1786 466341 • Fax: +44 (0) 1786 466100

www.nmahp-ru.ac.uk

If you have any questions please contact Karen Semple or Dr Helen Cheyne at the address below

**NMAHP Research Unit
Iris Murdoch Building
University of Stirling
Stirling
FK9 4LA**

Tel: 01786 466101

Email: karen.semple@stir.ac.uk or h.l.cheyne@stir.ac.uk

Please take time to think about this. If you would like to take part please fill in the attached form and return it to me using the attached envelope within 1 week.

✂-----

I am interested in being involved in the study and I am happy to be contacted about participating.

Name:

Email address:


Telephone number:

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Appendix 11

Participant Consent Form

 <small>Improving health through research</small>		
Professor Brian Williams, Director		
Iris Murdoch Building • University of Stirling • Stirling • FK9 4LA		
Tel: +44 (0) 1786 466341 • Fax: +44 (0) 1786 466100		
www.nmahp-ru.ac.uk		
Consent Form for all participants – Version 3, 15.12.2013		
Title of Project: Decision Making in Prosthetics		
Participant Identification Number for this study:	<div style="border: 1px solid black; width: 100px; height: 20px;"></div>	
CONSENT FORM		
This is the standard consent form that the Health Authority Ethics Committee asks people to sign when they take part in a research project. Please sign both copies and keep one for your own records. The other copy will be kept for our records.		
Name of Researcher: Karen Semple		
Please initial boxes		
1. I confirm that I have read and understand the information sheet (Version 3, 09.10.12) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	<div style="border: 1px solid black; width: 30px; height: 30px;"></div>	
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	<div style="border: 1px solid black; width: 30px; height: 30px;"></div>	
3. I agree to consent to my conversation being tape recorded.	<div style="border: 1px solid black; width: 30px; height: 30px;"></div>	
4. I understand that any part of my tape recorded conversation can be withdrawn from the study if I request it.	<div style="border: 1px solid black; width: 30px; height: 30px;"></div>	
5. I understand that if I lose capacity to consent, any identifiable data already collected will be retained and used in the study.	<div style="border: 1px solid black; width: 30px; height: 30px;"></div>	
6. I agree to consent to anonymised quotes of my interview being used in any publication or presentation of the research.	<div style="border: 1px solid black; width: 30px; height: 30px;"></div>	
7. I agree to take part in the above study.	<div style="border: 1px solid black; width: 30px; height: 30px;"></div>	
_____ Name of Participant	_____ Date	_____ Signature
_____ Researcher	_____ Date	_____ Signature
<small>NMAHP Research Unit is funded by the Chief Scientist Office, Scottish Government Bases at: Glasgow Caledonian University and University of Stirling The University of Stirling is a charity registered in Scotland, number SC 011159 Glasgow Caledonian University is a charity registered in Scotland, number SC 021474</small>		

Appendix 12

Lone worker policy

The procedure used was the Standard Operating Procedure for lone working within the NMAHP Research Unit, the procedure is set as follows:-

1. I provided a contact person (either one of my PhD supervisors, or the NMAHP Research Unit secretary) with the address of the interview location.
2. Prior to entering the location/beginning of the interview I phoned or text the contact person and highlighted when I expected to be finished that interview.
3. I then phoned the contact person immediately after leaving the interview location.

If there had was no communication from me after one hour from the commencement of the interview, the safety protocol was set as follows:

- a. The contact person would phone me.
- b. If I was still with the participant, and in the event that I had concerns for mine or the participants' safety a code word (prearranged with the contact person) would be used, after which the police would be called by the contact person who would raise their concerns and inform the police of my location.
- c. If the contact person was unable to make contact with me when they called then the police would be contacted as above.
- d. I would stop any interview in which I had concerns for my safety and inform the contact person that I had done so immediately upon leaving the interview.

